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ABSTRACT

Literature is reviewed on the effects on families of having a handicapped child, and a model of the interrelationship of effects is proposed. Topics covered in the discussion include the following: the meaning invested in handicap (labeling, the meaning to the parents, and the effects on the handicapped family member): caring for a handicapped child: and the changing nature of living with a handicapped child. The effects of the initial discovery and its stress on parents are examined, as well as the effects on the parents, the marriage, and the family's economic situation of life with a handicapped family member. Social life and leisure aspects are considered in a section on the effects on the family's relationship to the outside community. Sibling reactions and adjustments are noted. Factors such as birth order, sex, family size, and socioeconomic status which influence family adjustment are discussed. A final section suggests differences between families with normal and those with handicapped children, and between families of the mentally and the physically handicapped. (CL)

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Living with a Handicapped Child:

The Impact on the Family

A Literature Review

by
Elizabeth Gordon

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Jerusalem

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I. Introduction: The Scope and Organization of the Paper

Having a physically or mentally handicapped child in a family has the potential of having a profound impact on its functioning. The well being of each family member, their relationships with one another, and their relationship to the outside community may each be affected by the presence of the handicapped child. This paper presents a review of the literature detailing this impact. A fairly specialized literature, describing a wide variety of effects, is presented. Reference is made to empirical studies, theoretical works, experiential descriptions and previous literature reviews.

The literature pertaining to families with a mentally retarded child, and that referring to those with a physically handicapped child, are both included in this paper.

The decision to include both types of handicap in one comprehensive paper was made after a preliminary exploration of the available literature. It was found that the same effects on the family tended to be studied in regards to the two types of handicap; i.e. researchers investigating physical handicaps, and those investigating mental handicaps, both refer to initial impact, effects on parents' health, changes in the marital relationship, etc. Also, a number of authors in the field deal with the concept of handicap in general, or include a variety of handicaps in their work, so that conclusions reached are based on a consideration of both types of handicap. In addition, it became clear, in reading about handicapping conditions, that a clear line between mental and physical handicap is often difficult to conceptualize. Many conditions appear in the literature as having both a mental and a physical component; the mentally retarded may have a degree of physical handicap, and physically disabling conditions such as spina bifida, can also affect intelligence level. A unified, comprehensive review of the literature on effects described in families with both physically and mentally handicapped children, was thus decided upon. In order to enable the reader to fully understand the particular material referred to in a specific section, however, the type of handicap to which the author or researcher refers has been specified. In this way, those cases in which a specific effect is seen in relation to a particular type of handicap become apparent.

The available literature also dictated another decision regarding the scope of the paper. It quickly became clear that deliniating the effects on the family of the handicapped child when that child is an adult, was not possible. The interest of researchers and theoreticians in this field appears to be on handicapped offspring as children only. Literature on the effects of living with adult handicapped sons and daughters was not found to exist. A few articles on the effects of living with adolescent handicapped children represent the only literature found relating to older offspring.[1] Also, studies directed towards the subject of the effects of the handicapped on their families carried out in Israel were not found and so, could not be included.

These considerations are indications of the nature of a literature review, which takes its shape from the books and articles that exist in a field. As such, a review reflects the interests of particular authors in particular subjects. In reading a paper thus shaped, certain considerations should be kept in mind, to allow for accurate interpretation.

The research studies in this paper presented tend, in the main, to each focus on an investigation of a particular effect. With this kind of approach, the relative importance of the various effects described cannot be deduced. It should not be assumed, for instance, that should a particular effect on families be discussed in a large number of articles, that it is thus established as an especially frequent or, disturbing, phenomenon in families of the handicapped. A large body of research on a specific subject may reflect a number of factors other than its intrinsic importance. It may be a subject convenient to study, of special interest to certain researchers for some reason, be popular as a research subject and therefore easily funded, or, having been studied extensively, be especially amenable to researchers who seek to establish further refinements. As aspect on which little material is found is also, therefore, not necessarily an unimportant one, but may for opposite reasons, have been neglected as a subject of investigation.[2] The optimal way, then, to approach this survey of the literature is with the understanding that the effects on families presented here have all been described as occurring in families with handicapped children, and that some of these are better supported, and more extensively researched than others.

Turning to the organization of the review, first discussed is literature pertaining to the aspects of the situation that impact on the family; what it is about living with a handicapped child that has the potential of contributing to the specific effects seen. Following that is a consideration of the literature relating to the impact on the parents when they first learn of the child's handicap. The next section, Section IV, is considered the major thrust of the paper. It presents the literature detailing the effects on the family of living with a handicapped child. The focus of this section is on the parents of the child, and family functioning as a whole, although some mention of the effect on the child's siblings is made. The section following discusses the literature dealing with the difference in impact seen in different families; the factors that differentiate impact, and a consideration of those families whose adjustment to the situation is considered positive. The final section is composed of a number of insights on the literature which are shared with the reader, and a suggestion as to the use of a model in understanding the interrelationship of effects, which is seen as a potential aid to program-planning.

II. Aspects of the Situation that Create the Impact on the Family

A first step in understanding the multiple effects of having a handicapped family member involves a consideration of the factors inherent in the family's situation that have the potential of causing these effects. Most of the research reporting various effects observed, does not attempt to specify these factors, but rather relates to the family situation as a whole. The emphasis in much of the research tends to be a delineation of effects seen when a family includes a handicapped member, rather than a breakdown of specific causes. It is possible, however, to discern from the literature, including that of a more theoretical nature, what it is about the family's situation that is potentially disruptive and may cause the greatest impact. These aspects, then, are elements inherent in the situation of having a handicapped family member that, to a great extent, are responsible for the effects described and can potentially lead to the impact seen.

These elements have been divided into two major categories. The first relates to the literature dealing with the more psychological or philosophical aspects of the situation; the meaning invested in having a handicap, by the society at large, the family, and the handicapped person himself. The second relates to that describing the practical difficulties the family faces in caring for its handicapped member. It is usually not possible to determine the extent to which elements belonging to a specific category contribute to an effect seen. Rather, it is suggested, it is a combination of factors that likely brings about most effects. The attempt here, then, is not to suggest relationships between specific causes and effects, but rather to present a background of factors against which the impact described can be understood.[3]

A third element of the background of factors to be described, is the fact that it is in flux, changing over time. Raising a handicapped child, as in raising a normal child, involves different emotions, responsibilities, problems, etc., at different stages of the child's life. Of particular interest in this respect will be literature describing specific crisis points in the lives of parents raising a handicapped child.

A. The Meaning Invested in Handicap

1. Being "Labelled" and the Associated Societal Stigma

Children with handicaps are born into families in the general population who, in the main, don't differ significantly from other families. With the birth (or discovery) of a disabled child, they become, in perhaps one stroke, different in a significant sense from other families; both in society's eyes and in their own. The family becomes labelled as one containing a handicapped member, and the meaning of this label can play a large part in the family's life. How the family deals with both society's attitudes, and their own feelings, towards this label contributes to determining the impact of the handicap on the member's lives.

That this label is imbued with a sense of defect, deviance and especially social stigma by the general public has been pointed out by a number of authors. Holt states that "there is a strong social stigma against mentally retarded individuals. This is evident in the stares and comments that follow a defective child down the street."[4] Kew indicates a great deal of public embarassment and ambivalence in regards to the handicapped stating that "social stigma is responsible for many of the problems."[5] He sees social discrimination against the handicapped as an enduring and pervasive problem, and feels that the "stigma borne by the family eats away at parental confidence and plays upon feelings of guilt and shame."[6]

That the handicap is regarded as deviant, is borne out by references to the awkwardness with which the public deals with the handicapped individuals. People may be acutely uncomfortable upon seeing a handicapped person. They simply don't know how to act, and may wind up either ignoring the handicapped individual, or being over-solicitious. As McMichael has pointed out, "In any case, the handicap itself will be an object of curiosity to most people, evoking either their pity or their aversion and making it difficult for them to be at ease with the child concerned. People who are unsure of themselves in such a situation will tend to be over-emphatic, embarrassing the child with too much concern or pretending too obviously to ignore his difficulties."[7] Every public excursion may involve stares, comments, etc., and may never be able to be carried out unobtrusively, in the way that other families take for granted.

That the family of the handicapped person, and not only the handicapped individual himself, is stigmatized by society is suggested by Birenbaum. He sees the parents of the mentally retarded as having a courtesy stigma that they must seek to manage. "Courtesy stigma", a term coined by Goffman, refers to a "spoiled identity because of sharing a web of affiliation with the stigmatized."[8] In this conception, individuals in a family have to deal with the fact that, because of the presence of a particular family member, they are all seen by society in a negative light. Society's attitudes toward them, and the feeling of being deviant from the norm, are aspects of the situation that may be constant for families of the handicapped, and may have a continual influence on their lives.

A related factor described in the literature involves the parents own attitudes towards handicap, the fact that they may themselves share the attitudes of the society at large. Wolfensberger and Menoloscino, in this context suggest that "many people must have conflicts about a retarded child not because the child is an extraordinary burden of care but because they intensely dislike the meaning which the child represents."[9] They propose such value conflicts, defined as"culturally mediated attitudes toward defect or deviance"[10] as a major source of parental management needs in parents of the mentally retarded. The authors stress the "powerful effects of social and subcultural values which are transmitted in a relatively 'normal' fashion and which may rule a persons behavior."[11] The parents then are in the position of having absorbed society's values and attitudes toward handicap. As they are members of that society, these reflect their own feelings, which they then must deal with as regards their own family.

2. The Meaning to the Parents of Having an Abnormal Child

Another aspect of the philosophical meaning of having a handicapped child that sets the background for the effects seen is the parents feelings as to having a child who is not normal. Ryckman and Henderson[12] focus on this aspect. Their discussion involves a consideration of how, in terms of meaning, having a retarded child is different from having a normal child; the realization that all that is invested in a normal child, and expected of him in the course of his life, cannot be the same when a retarded child is involved. The authors see the meaning of a normal child to his parents as including a number of elements: he is viewed as a physical and psychological extension of the parents, he is felt to be a means of vicarous satisfaction to his parents, he is a personalized love object, and he is a means by which they can transcend death and derive some measure of immortality. These are considered as not having the same meaning when the child is retarded. Consideration of the child as a product of oneself, leads to feelings of inadequacy when the child in question is retarded, assert Ryckman and Henderson.

They point to a number of authors as indicating a sense of loss when parents realize that their child cannot provide vicarious satisfaction and fulfill their hopes and desires. Parents are described as feeling that they do not love their defective child as they feel they should. Retarded children are seen as unable to fulfill the function of providing parents with a kind of immortality.

Rather, it is asserted, parents feel that these children can't be looked to to carry on the family name and traditions. Wofensberger also mentions this aspect, quoting Buck's description of the parents' feelings as "the stream of the generations is stopped" and that the parents will not live on in the children after death.[13]

This area of meaning for parents, the understanding of the limitations of their parental hopes and aspirations that must be involved when a child is retarded,[14] may be a continued emotional undercurrent to their lives. As such, it can help to set the stage for the impact on the family of the handicapped that is seen to occur.

3. The Meaning of the Handicap to the Handicapped Family Member

Another aspect of having a handicapped member of the family that is a factor in the impact seen, is the handicapped person's feelings about himself. The handicap person's dealing with the issues, that arise when he comes of age to realize the implications of being handicapped, can effect the impact on the family as a whole. These issues appear to be similar to those his parents have faced upon learning of the handicap. Like his parents, he experiences the "label" and stigma of handicap, worries about what the future holds for him, etc. Also, as McMichael has pointed out, "He may also perceive only too well the difficulties his handicap has caused his parents",[15] the extra demands made on family members, the effects on his mother's health, etc. This may lead to feelings of depression and isolation.

McMichael has described this process in regards to physically handicapped children:

> As the child grows older he becomes aware for himself that he is different. He must then start the long process of adapting himself to his handicap. At first he naturally wants to know why he is different and if he will ever be 'better' like other children: 'Shall I be able to walk and run and play?' 'Shall I always have to be in a chair?' 'What shall I do when I'm grown up?' If he is an elder child and the new baby can crawl and toddle, and eventually walk, he will want to know why the baby can do all the things he cannot do. So the long series of crises in emotional adjustment goes on. Through these the child either learns to accept his limitations or to resent them. He may become depressed and anxious in accepting them or agressive and quite difficult because he cannot accept them and resents the everlasting frustrations they impose.[16]

It is perhaps obvious that whatever the child's emotional reaction, it will play a part in determining the functioning of the family members who must live with it.[17]

There are a number of research studies which document the emotional crises that the handicapped child may experience. In McMichael's research on 50 severely physically handicapped children, she assessed that 22, or 44%, had normal or slight emotional difficulties in adjusting to their handicap. For 28, or 56%, the emotional difficulty was judged to be moderate or severe.[18] She points out the particular emotional susceptibility of children whose handicaps are acquired, asserting that they "may be almost overwhelmed for a time by their inability to continue to take part in activities they previously enjoyed..."[19]

Kolin and his associates report depression as evident in 3 of the 13 children with spina bifida, aged 7-11, that they studied.[20]

Minde et al closely followed a group of 41 severely physically handicapped children through their first few years of school. The sample separated into two groups; there were 20 children considered retarded, with IQ's under 80, and 21 nonretarded, with IQ's above 80. They found that most children underwent two well-defined crises related to specific developmental hurdles between the ages of 5 and 9. Isolation, and increasing definition as a handicapped child were found to occur. The authors found that, "Although each child was said to be fully accepted by his peer group when admitted to the school, their previously tolerant friends at home had grown up from sandbox toddlers to baseball and hockey players and now wanted little or nothing to do with him."[21] This isolation from normal peer-group activities together with the realization of the likely persistence of their handicap, coincided and possibly lead to a severe depressive period in 16 children; 12 of these of normal intelligence and 4 retarded. The authors conclude that a stage in the development of handicapped children between 5 and 9 involves a "cognitive realization, triggered by a loss of his outside peer group and exposure to other (older) crippled children, that his handicap was not going to suddenly disappear. This insight frequently lead to a severe depressive period."[22]

Dorner discusses adolescence as being a similar crisis period for the physically handicapped. He interviewed parents of 63 handicapped adolescents aged 13 to 19. He found that "many parents reported increasing social isolation of their child with the onset of adolescence. What non-handicapped friends they may have had earlier tended to dwindle in numbers as these friends found jobs and formed sexual relationships."[23] The author classified 50% of these teenagers as severely socially isolated; they had not been visited at home, nor had they themselves visited or gone out with any friends their age, handicapped or non-handicapped, for at least one month prior to interview.[24]

B. Caring for a Handicapped Child

1. The Care Involved on a Day-to-Day Basis

In reading the literature on the handicapped child in his family, one cannot but be struck by the often extraordinary burden of care that is involved on a day-to-day basis. The degree of care is, at times, described as over-whelming and totally pre-occupying, so that family members, especially mothers, may do virtually nothing but care for the child, and in any odd moments when care is not required, be too exhausted to do anything else.

Caring for the handicapped family member has been described as a major factor in determining the effects of various handicaps on the family. Wolfensberger & Menolascino see the stress arising from the situational demands of raising or caring for a retarded person as "reality stress".[25] This stress is described as a normative reaction to situational stress, crises or conflicts due to excessive reality demands. They consider such reality stress to be one of the major sources of parental management needs for parents of retarded. Anderson and Spain, talking of families with spina bifida children, indicate that "on a day to day basis, the oridinary routine of living will be disturbed and the necessity to make special arrangements to accomodate the child and his disability will become a major consideration."[26] Kew, referring to factors working against the restoration of satisfactory equilibrium in families with handicapped children, also points to the "special problems of care which actively disrupt the normal functioning of the family and often demand a redefinition of roles among its members."[27] He sees the care problems of families with physically handicapped as "related to the physical dependency of the child which demands redistribution of time and attention on the part of parents, behavior difficulties arising from handicap, special education and medical needs, the difficulty of transportation and finding suitable accomodation."[28] He points out that the family is required to absorb the full strain of meeting practical needs.

Hannam speaks of the "slow grind of bringing up the child"[29] that the parents of the mentally retarded must face. He goes on to "dispel the myth that all mongols are affectionate, lovable and cuddly" by describing the annoying behavior traits that they often exhibit.

The literature is replete with descriptions of the specific difficulties involving in taking care of handicapped children. Howell describes the situation in regard to the physically handicapped:

> Fatigue appears to be a way of life for many parents of handicapped children. Some of the children require almost 24 hour nursing care. With other children there may be physical fatigue of parents caused by heavy lifting, bathing, dressing and frequent visits for medical care and educational problems. Chronic low back pain is a frequent cause

> of complaint from mothers of heavy children with c.p....(There) also may be unpredictable emergency visits to the hospital in the middle of the night; like those of sudden midnight episodes of croup in mongoloid. Upper respiratory infection often keep parents awake; physical fatigue is augumented by lack of sleep.[30]

Holt's work is perhaps the most detailed dealing specifically with the daily care involved when a handicapped child is in the home. He focuses on the families of 201 families of the severely retarded. He found that "The retarded children required more care and attention than normal children. Some however were exceptionally troublesome and these can be considered in three groups - those requiring nursing care; those needing constant supervision because of their aggressiveness or restlessness, and those needing attention at night."[31] He discusses each of these categories in detail. The group needing nursing care,"could not walk, had to be fed, bathed and dressed and were incontinent."[32] In terms of supervision, he found that "in 63 families the children's behavior was so difficult that constant supervision was essential; destructiveness, exceptionally aggressive, restless, wandered away from home. Several parents had to resort to extreme measures...One mother...kept a toilet bucket for her own use downstairs, carrying from room to room, so that she need never leave the child unattended."[33] Some mothers never left the defective child.

Mercer's study is especially salient in understanding the importance of care problems in the life of families with handicapped children. He compared a group of mentally retarded individuals placed in a public hospital and subsequently released to their families, with a similar group who did not return to their families. He explored the problems encountered with the retarded family member at home, before institutionalization. He found that, "although practically all problems showed a higher percentage of the families of the residential patients reporting the problem, the significant differences were concentrated in one area - burden of care. These problems have in common the fact that they all involved physical or economic demands made upon the family social system by the retardate; cost of his support, exhaustion of mother, requirement for constant supervision, medical care, and demands of frequent seizures."[34] His conclusion is that "When the mosaic of family problems includes...a load of physical care, the family is less likely to countenance the return."[35] "In released patients, the preinstitutionalization crisis...seldom involved demands on other family members of excessive physical care."[36]

2. The Most Difficult Aspect of Care

There is some discussion in the literature as to the most difficult aspect of the care of the handicapped person. It is clear that this depends to a great degree on the specific handicap of the child, but it remains of interest to discover those aspects likely to be most troubling to parents should they occur.

Some authors stress the physical aspects of care as those most difficult, others the mental difficulties of the child, and problems in communication with him. Hannan sees the greatest difficulty as a psychological one of difference of expectations in regards to a retarded child, rather than a normal one: "With a normal child the stages of development merge and pass and however ghastly the mess, one knows that in due course toilet-training will be achieved, speech will come and the usual social skills will be acquired. The mentally handicapped child often moves ahead so slowly that one despairs of ever achieving the next stage."[37] He also specifically points to many of the parents as mentioning the speech problem as especially troubling,"when the child is unable to speak, a number of problems arise."[38]

Ehlers similarly feels that the parents most difficult problems lay with the lack of speech or its intelligibility. He concludes that parents "perhaps felt that if only the child could or would talk that somehow they could get through to him."[39] Barsch, also referring to mentally handicapped, also emphasizes this type of problem as the most difficult, "the medical nature of the child's problem is a far less influential factor in child-rearing than the child's level of intelligence. Problems in communication and learning present more dilemmas to the parent than the sensory loss or the physical handicap."[40]

Begad stresses the physical care difficulties of the mentally retarded, "The problems presented are directly related to the degree of dependency in the child. Among the severely handicapped, many require nursing care around the clock. They cannot walk, bath, dress or feed themselves. Some require constant care, not only during the waking hours, but also at night."[41] He continues, "The behavior and developmental growth patterns of the profoundly and severely retarded often present management problems as well. Sensorimotor handicaps may interfere with development of self-care skills, and bowel and bladder training may be difficult, not only because of the child's limited comprehension, but also because his nervous system has not matured sufficiently to permit voluntary control over these functions."[42] Begad also indicates the presence or absence of central nervous system pathology as an important factor. "Where pathology exists, behavior is often excitable, unpredictable, or uncontrollable. Frequently, the individual is hyperactive, aggressive, or destructive and has difficulty in conforming to externally imposed controls. Most (brain damaged children) are self-centered, have low tolerance for frustration and tend to seek immediate satisfaction of needs."[43]

Holt, as was noted in the previous section, found three aspects of care especially troublesome for parents of severely retarded: 1) nursing care of children who could not walk, had to be fed, bathed and dressed, and were incontinent, 2) constant supervision of children who were especially destructive, aggressive, or restless and 3) having to provide attention at night.[44]

Richard and McIntosh, in a study of 86 families of spina bifida children, found two principal difficulties cited: 35 families mentioned lifting and 10, incontinence. Another 5 families cited the need for constant care as their principal difficulty.[45]

Bradshaw and Lawton's study of stress in mothers of severely handicapped children also provides insight into the aspects that families find most difficult. They investigated a large number of factors to see which of these caused variation in the scores of the mothers on an inventory measuring stress. Most aspects involved in care of the child were found not to cause significant variation: whether child was incontinent, needed to be fed, his degree of handicap, etc. A number of aspects of management of the child are cited as causing variation in the stress scores: "Mothers of children needing frequent night attention had higher scores than others. Mothers of children who played normally had lower scores. Mothers who reported their child's health as normal had lower scores than those who reported it as fair or good and there was also some variation in score found according to the number of times the child had had to be a hospital inpatient. Finally, some variation in scores according to degree of activity reported by the mother was found: mothers of normally active children had lower stress scores than mothers of both underactive and hyperactive children."[46]

C. The Developmental Process Involved

Another element in understanding the background of factors against which the impact on the family occurs, is the fact that living with a handicapped person involves a dynamic rather than static process. Change occurs with the years, so that the background may be constantly evolving as various factors come to the fore, or lessen in importance. A number of authors speak, in this regard, of crisis points in the raising of handicapped children, when difficulties may be especially acute.

Begab speaks of this in regards to the parents of mentally retarded:

> The educational needs of parents...are in a state of constant flux. As the child passes each developmental milestone, new crises may arise. School brings new social relationships, competition, and for the mildly retarded whose mental impairment is not yet identified, frustration and failure. Puberty and adolescence, troublesome for most youngsters, may present special problems for the parents of the mildly handicapped, yet paradoxically few for the parents of the severely handicapped. Adulthood poses new demands for economic and social self-sufficiency and other obstacles that the retarded person and his family must hurdle.[47]

He further points out that, "for many parents the onset of puberty in their child is a signal for panic,"[48] with fear of sexual misconduct evident.

Freeston points out areas of stress for parents of spina bifida. Among these are a number that relate to specific events in raising the child. He cites the impact of birth, the first hospital admission, out-patients visits and subsequent home admissions as specifically stressful times.[49] Drotor points to recurrent hospitalizations required for care as "intensifying parental anxiety which had been created by birth and might start the process of reactions over again."[50]He was referring to parents with children with a wode range of congenital malformations, including mongolism and congenital heart disease.

MacKeith outlines crisis periods during the growth of the handicapped child. He contends that the following are times of crisis for the parents: 1) When parents first learn about or suspect handicap, 2) When, at about age five, decision has to be reached as to whether the child will be able to go to ordinary school, 3) When the handicapped person comes to the time of leaving school: both the parents and the handicapped person realize that cure is never going to happen and they wonder whether he or she will be independent and able to work, while the handicapped person wonders whether he or she will be able to meet girls and boys, make love and marry. 4) When the parents become older and unable to care for their handicapped child.[51]

It also might be speculated that, emotional crisis points for the physically handicapped person himself, as described by Minde et al and Dorner above, are likely to be crisis points for the family. These are, as described by Minde et al, the early school years when the child first defines himself as handicapped and realizes the handicap is permanent, and, as Dorner indicates, adolescence, when social isolation is likely to be severe. Also, especially in regards to physical handicap, it should be realized the disease process itself may be progressive, bringing changes in the child's functioning, and, it may be assumed, significantly changing the parents' emotional outlook and practical responsibilities.

While reading the next section of the paper, which deals with the specific effect of having a handicapped family member on the family, it might be useful to keep in mind the present discussion. That is, although the research to be described details a great number of specific effects seen, these are not, in the main, tied to specific conditions in the family leading to these effects. The state of the art simply does not permit this. Recognizing that these families have had to deal with attitudes towards handicap, as society at large, they themselves and their handicapped children experience them, as well as often extreme child are problems, and that these elements change with time, can serve to enhance understanding of the effects described.

III. The Initial Impact

A. The Discovery That the Child is Handicapped

Although the focus of this paper is to be the effects on the family of living with a handicapped person, it is felt that some discussion should be made of the initial impact of the discovery that the child is handicapped. Much literature, both theoretical and descriptive, exists which deals with this initial period; the shock of discovery, and the stages the family members go through, more or less successfully, in dealing with this event. There are some authors who maintain that the effects of this period may never entirely fade, but rather serve as a constant undercurrent to the interaction of family and child.

Much of the literature deals with those mental and physical handicaps which are discovered at birth. They are clearly more amenable to an investigation on this point, then handicaps which are discovered after a long period of suspecting that something is wrong with the child. A number of authors theorize that all expectant couples visualize a perfect infant and have a set of expectations regarding him, and that these prenatal views have to be readjusted when the real child appears. This readjustment is clearly much more extreme when the child is handicapped. Also, the time of birth is seen as always being a period of stress for parents, which is again, exacerbated when the birth is of an abnormal baby.

McMichael, and Anderson and Spain, discuss difficulties in the period immediately following the birth of a physically handicapped child. They also point to factors likely to make the emotional impact especially severe. McMichael, reports that, "It is impossible to talk to the parents of a handicapped child for any length of time without becoming aware of the shock and agony of mind which many of them have passed through during those first critical weeks. They have had to face their families and in-laws, their neighbors, and, most painful of all perhaps, themselves, with a baby who is not quite perfect and may even be deformed."[52] She continues, "Although in every case the problems differed, the handicap itself clearly involved an emotional crisis for the parents. Where they had been told that the prognosis was grave, or that the child would be unlikely to survive adolescence, the strains and tensions appeared almost unbearable. In the case of inherited diseases...the parents' profound sense of guilt created its own emotional complications."[53] In this context, she later points to "the tendency for each partner to blame the other if the handicap is congenital."[54]

Anderson and Spain, referring to parents of children with spina bifida, assert that, "It is in this context of shock, disappointment, bewilderment, and unreality...that the spina bifida child enters his family. Even the most well-adjusted parents with the most stable and loving marital relationship are likely to be overwhelmed, at least temporarily. For the unmarried mother, or where the marital relationship is poor or the pregnancy unwelcome, the effect may be devastating."[55] They also point out that approximately 40% of spina bifida births are first children. The authors feel that, "For these mothers in particular the first months at home with the baby are very difficult ones. Caring for a first baby, learning how to handle him, interpreting his needs and judging the seriousness of his ailments, has problems for any young mother. When, in addition, he suffers from a serious condition, the nature of which may still not be very clear to her, the anxiety produced can be very great indeed."[56]

1. The Predominate Parental Emotion

There has been much discussion in the literature as to the emotion that predominates when parents discover a handicap in their child. Disbelief, shock ,guilt, anger, rage, confusion, and self-pity have all been mentioned in this context. In one article, Wolfensberger & Menolascino, focus on the shock of the discovery and propose "novelty shock", defined as when parents learn that their expectations and perceptions in regard to their child deviate substantially from reality, as being a major source of parental management needs.[57] In a second article, Wolfensberger reviews in detail the literature on initial emotional reaction.[58] He mentions authors who propose grief as the major initial reaction to the birth of a retarded child. Solnit and Stark are indicated as conceiving of parents of a retarded child as being in chronic mourning for their "object loss" of the expected healthy baby, to which the advent of the retarded child is related. Similarly, Beddie and Osmond are cited as equating parental response to a retarded child as equivalent to a "child loss"; the death of a normal child. Olshansky is mentioned as seeing these parents as being in a state of "chronic sorrow".

Wolfensberger also discusses literature indicating ambivalence, and frustration as the principal initial emotion. He finds the most prevalent parental reaction mentioned in the literature to be guilt; "why did it happen to me?", accompanied by a review of all possible causes, He, however, feels that "writers generally imply that parental guilt is usually without a reality basis and leads to maladaptive and nonadaptive behavior".[59] In more recent years, Wolfenberger indicates that writers have become more skeptical as to universality of guilt; use of regret is mentioned as a better term.

2. Stages of Adjustment to the Discovery

Many authors have described a series of stages through which parents are considered to advance after discovery of their baby's handicap. Each author's conception is slightly different, and may involve from 3 to 5 stages. Usually included are initial stages of intense emotional reaction - grief, shock, anger, etc., followed by a period of coming to accept the reality of the handicap, and then a final period of adaptation and reorganization of family life to the realities and conditions. Some families are considered to achieve this better than others; some remain fixed at early stages of adjustment. Some specific authors' conceptions of such stages will be discussed.

Cohen postulates four stages of adjustment to either mental or physical handicap: 1) experiencing grief, 2) learning to handle anger, 3) adjusting adaptive patterns, 4) making reality adjustments.[60] Drotar et al describe five stages in the adaptation of parents to the birth of an infant with a congenital malformation: 1) shock 2) denial 3) sadness 4) anger 5) adaptation and reorganization.[61] They add that parents who each had a different time duration at each stage didn't share feelings and had difficulty in relating, which often resulted in temporary emotional separation. Wolfensberger describes the three stages mentioned in the Mental Retardation Handbook of the American Medical Association of 1965: 1) initial emotional disorganization, 2) gradual reintegration, 3) mature adaptation, which is not achieved by all.[62]

Wolfensberger points out that few writers deal with retardation of relatively sudden but late onset, or of early onset but insidious manifestation because of mildness.[63] Willner and Crane, in a recent article, deal with a related area, previously neglected in research. They investigated the mourning process occuring when parents learn, at a late date, that their children are marginally handicapped. The authors based their work on Solnit and Stark's earlier finding that mothers of retarded babies experience the same sequence of emotions undergone by those who mourn an actual death - denial, anger, despair, and acceptance. The completion of these four stages was considered essential if the mother was to emerge from mourning. Willner and Crane query whether, "Given a considerable lapse of time before the parents first learn...that there is a significant delay or disorder in their child's development, do Solnit and Stark's ideas about mourning apply?" Their study indicated that these findings did apply but that with the marginally handicapped the reaction was less severe, and the entire process was prolonged.[64]

In terms of initial parent reaction as related to severity of child's handicap, Wolfensberger indicates two schools of thought as regards mental retardation. Some authors are cited as feeling that mild retardation causes the more intense reaction, and others that severe retardation does.[65] In one conception, parents of severely retarded children are seen as having an easier adjustment to the initial impact because the condition is more obvious. Dehoff in this respect, is described as feeling that uncertainty of the future has the greatest impact on the mother-child relation, and that this explains why some mothers of severely handicapped children have an easier time. In contrast, Auerback is mentioned as finding parents of the severely handicapped, especially if the parents are older, as more depressed. Also, Cair and Levine are cited as finding mothers more adaptable to children of higher ability levels at least while children are young.

Wolfensberger, in his comments on the literature he reviewed, points out that in most cases "the description of early impact is based mostly on subjective experiental impressions and self-reporting by parents."[66] He therefore questions their validity and adequacy. It could also be questioned whether underreporting of parents with less severe reactions tends to occur. Wolfensberger also feels that you cannot expect all parents to undergo the same reactions "as some writers seem to think."[67] Personality differences, as well as those of social class, education, religion, etc., would be expected to make for differences in parental response.

B. Continued Parental Reaction

Wolfensberger asserts that initial impact can be severe and profound, and coping with it unsuccessful or incomplete.[68] This is seen as leading to repeated crises, and chronically poor mental health of the parents. He cites a number of findings related to this. Auerback is mentioned as finding that parents of retarded displayed much more intense feelings than parents of normal children, even when years had passed. They were found to show an unexhaustable need for catharsis. Kramm is cited as finding that the initial reaction failed to dissipate after as much as five years, and that in 16% of his sample, parents were too emotional to discuss the child with each other. Thurston's research is pointed out as findings that even when as much as 15 years had passed, time had done little to dissipate initial reactions of helplessness, grief and guilt. He is mentioned as finding emotional disturbance and unhappiness much in evidence. Holt is also said to have found that many parents are unable to overcome their earlier feelings of frustration and disappointment. This long-range conflict was generally indicated as more likely in upper-class than lower-class families.

IV. The Effects of Living with the Handicapped Child

A. The Effect on the Parents of the Handicapped Child

1. The Impact on Physical and Mental Health

The literature, both impressionistic and empirical, stresses the effects that living with a handicapped child has on the parents. The evidence available tends to support the view that bringing up a handicapped child has adverse effects on parents' physical and emotional health. The mother is often singled out as bearing the greatest burden of care, and thus, being likely to experience ill-effects. This has been found to be true for parents of both mentally retarded and physically handicapped children.

Holt, in his study of 201 families of severely retarded children, found both physical and mental health of the parents to be affected. He reported that, "In most of families the mother bore the heaviest burden of work. Many of them appeared to be in poor health. They were pale and worn out by the strain of caring for their retarded children. Thirty-eight severe examples were noted. Some of these 38 mothers had large families and were from the poorer classes. They might have been exhausted anyway but their condition appeared to be aggravated by the extra care needed for the retarded child."[69] His descriptions of some of these cases indicates the severity of the effects that may be seen: "Stories of weight loss are common. One mother had lost 31 kg. in weight in the first four years of the child's life. Several broke down completely and had to be treated in hospital. Two mothers with chronic illnesses refused to have treatment rather than leave their children...Two mothers attempted suicide. She (the first of these) attempted suicide at a time when she appeared to be experiencing an intense conflict between devotion to the child and guilt caused by realization of the extent she had neglected her husband and normal children. (The other woman) attempted suicide at a moment of complete dispair."[70] Holt found the father's health to be adversely affected by the presence of the retarded child less often than was that of the mother. Of 11 cases in which this was reported, in 7 the strain of caring for the retarded child had exhausted both parents. Holt goes on to describe the emotional disturbances found in the parents in his study. "It was not possible to talk to the parents of these children without realizing the deep disturbances caused by their child's condition. In not one of the families I visited did I consider that the parents had made a full emotional adjustment to the problem..."[71]

The Carnegie study of mentally handicapped children in Glasgow found similar problems. In this study, two groups of children were investigated, a younger group of 22 children under 5 years old, and an older group of 39 children from 5 to 13 years old. In regards to the younger group, it was found that, "In nine cases ill-health of the mother seemed to be attributed directly to worry about the child and his behavior; in two of the cases the husband was more concerned about his wife's ill-health than the child's disability."[72] The parents of the older group were found to suffer from ill-effects to a greater degree. "In this older age-group there was a greater evidence of difficulty within the family arising from the presence of the handicapped child and his behavior. In nearly every case where the child was home, unplaced, there was a degree of ill-health of the mother from nervous tension and the constant need to supervise the child both by day and by night. This night supervision tended to fall on the mother almost exclusively, as the father had to have what sleep was possible in order to carry on at his work."[73] In contrast, the Carnegie study of 33 mentally handicapped children in Shropshire county found "no cases of marked ill-health in the mother" and the researchers "impressed by the way in which the parents as a whole were standing up to the long strain."[74] This difference between parents in the two counties appear to reflect a difference in housing conditions, and, perhaps, socio-economic levels, between the two areas.

Fatigue and chronic back pain have been noted by Howell as major problems for parents of handicapped children. "Fatigue appears to be a way of life for many parents of handicapped children. Some of these children require almost 24 hour nursing care. With other parents there may be physical fatigue of parents caused by heavy lifting, bathing, dressing and frequent visit for medical care and educational programs."[75] He explains that, "it is understandable how physical fatigue can affect a mother who is constantly maintaining watch over her child, either to keep him from hurting himself or others or to protect family furnishings."[76] Howell also found "chronic low back pain is a frequent cause of complaint from mothers of a heavy child with cerebral palsy."[77]

Walker and associates' research on physical and mental well-being of parents of spina bifida also indicates that these parents, especially mothers, tend to suffer from physical or emotional problems. Only 19 of the 98 mothers in the sample rated themselves as feeling fit and well. The largest number, 56 complained of being tired, worried or depressed, and 23 described themselves as substantially worried. The fathers presented a different picture, with 40 out of 77 declaring themselves well, only 8 as tired, worried and depressed, and 29, tired and anxious.[78]

McMichael, in her study of 50 children at a primary day school for the physically handicapped, found problems of emotional and physical health among the parents. She states that "...in addition to the 12 children and their parents who had been referred for child guidance, 6 parents were receiving psychiatric therapy. Two mothers were attending hospital regularly for psychiatric treatment and two saw a psychologist regularly; two fathers were suffering from chronic anxiety and a duodenal ulcer...There was much additional chronic physical and mental ill health among mothers and fathers, which obviously both reflected and increased their anxieties."[79] She also points out that "poor health in any member of the family, particularly the mother, adds to the strain on any family with a handicapped child."[80] In the 50 families, she found that 21 near relatives were under a hospital or doctor's care, and that 24 mothers reported suffering from a chronic illness or physical disability. In addition, "on closer questioning, another 14 answered that they were suffering from various complaints."[81] In terms of mental health, McMichael asserts that "almost 2/3 of the mothers suffered from varying degrees of anxiety, depression, tension or fatigue directly related to the handicapped child."[82]

A number of studies have focused on the depression and strain evidenced in parents of handicapped children. Dorner's study of parents of 63 adolescents with spina bifida found maternal depression to be in evidence. "Moderate or marked depression does occur more frequently in mothers in this study than in mothers of randomly selected 14½ year olds of similar social class."[83] (31.9% of his sample, as opposed to 15.1% of those randomly selected, were found to suffer from marked depression.) Dorner also concludes that "mothers in this study were more vulnerable and more likely to become depressed by other problems in their lives as a result of the chronic stress imposed over the years by having a handicapped child."[84]

Erickson, using results from MMPI's, found that parents of retarded children "have greater than average physical symptoms of psychogenetic origin, anxiety and depression."[85] This sample was comprised of parents of 76 retarded children aged three years old or under. While finding that most of MMPI scale means were significantly higher for the sample than for the MMPI norm group, Erickson, however, points out that the majority were in within normal limits, indicating that the stress reactions were of less than pathological intensity. The author also suggests that it be kept in mind that MMPI norm groups, while comprised predominantly of parents, were not necessarily of parents of young children. The implication appears to be that with the latter group, whose scores might conceivably be higher as the basis for comparison, differences between it and the study sample might have proved less than significant.

Two studies of stress used a "malaise inventory" in which "mothers answered yes or no to questions which refer either to emotional states or physical states with a psychological association."[86] The number of these items answered positively was the mother's stress score. Tew and Lawrence's study of mothers of children with spina bifida found that these mothers had higher stress scores, as measured by the malaise inventory, than mothers of children with psychiatric problems, brain disorders and physical handicaps. In addition, it was the author's impression that "many mothers struggle through illnesses that probably would incapcitate parents without such a dependent child, at the expense of the well-being of other members of the family."[87] The other study using this inventory was that of Bradshaw and Lawton's work on 303 families with very severely disabled children with a variety of disabilities. In this study, the average level of stress of the mothers was found to be higher that "that found in any other sample to which the scale has been applied."[88] They note that the mean score of 9.02 of their sample was twice that of the general population, and indicate that scores over 5 or 6 are outside the normal range and show evidence of disturbance. They point out that "9.02 is similar to the mean score found by Tew and Lawrence in mothers of severely handicapped spina bifida children and it is probably the mean score that one can expect to get in a sample of mothers of very severely disabled children."[89] The researchers found that although the degree of stress experienced by the mother was partly due to features of her environment (financial resources, whether she was able to work outside the home if she so wished, the amount of help and support received from relatives and friends, the child's health, whether the child played normally and whether he was nromally active), these factors were not by themselves enough to explain why some mothers experienced comparitively little stress and others a great deal. They suggest an alternative hypothesis, that the level of stress is determined by internal factors - by the physiology and personality of the mother - and that these internal factors are not affected in any specific way by the external social and physical conditions of the family and the child.[90]

Cummings et al investigated depression and stress as aspects of their comparing mothers of mentally retarded, chronically ill and neurotic children. Their results lead them to assert that "Comparison of selected personality features of 4 groups of mothers supported the common clinical observation that having a child who is deficient in health or adaptive competence is a physcologically stressful experience for the mother. The mothers of mentally retarded children appeared to experience greater psychological stress than the mothers of chronically ill children."[91] It was found that the mothers of mentally retarded children "clearly derive less pleasure in relating to the retarded child than in relating with their normal child. As a result of having a retarded child they bear a burden of anxiety, depression and conflict in modulating hostile feelings, at least relative to the retarded child and it seems likely with other persons as well..."[92] These mothers were also found to feel less competent as mothers: "reduced self-esteem relative to the maternal role is poignantly evident in these mothers."[93] This last finding, was also found by Love. He explains, "often the (mentally retarded) child's behavior is characterized by disorderliness, disorganization and low frustration tolerance. As a result he responds poorly to mothering. This causes the mother to feel inadequate as a mother because she cannot meet the child's needs."[94]

Cummings et al later report a similar investigation of fathers. Like the mothers previously studied, fathers were divided into four groups. Half of the fathers were the husbands of the women who had participated in the earlier study, each group having children with a different diagnosis. It was found that "fathers of mentally retarded experience a greater negative impact from fathering the child than do fathers of chronically ill."[95] In terms of stress, it is reported that

"...fathers experience significant stress as parents of a retarded child, even when have experienced the pleasures of having one or more healthy children."[96] In addition, the researchers found "indications that many fathers of mentally retarded children undergo long-term personality changes which resemble a pattern of pattern of neurotic-like construction."[97] Cummings et al present a severe view of these fathers, in their assertion that "There can be little doubt that the pattern of many of these fathers - with lowered self-esteem, depressive feelings, little sense of themselves as competent fathers, few satisfactions from family relationships, a need for compuslive ordering of their experience and tight control of social and sexual interests - indicates a mid-life augmentation of earlier neurotic tendencies,"[98]

A number of studies report findings in a different direction; they indicate that mental health does not differ markedly for mothers of mentally retarded and normal babies. Waisbren studied 60 parent couples with a child less than 1.5 years old. Thirty couples had a retarded, and thirty, a normal child. Half of the couples lived in the United States and half in Denmark. She found that, "In the first year and a half, parents with a developmentally disabled child were strikingly similar to parents with a non-handicapped child on most dimensions relative to coping with a new baby. For example, their reports of their physical health, social activities, activities with the baby, marital relations, and plans for the future did not differ to a significant degree.

Many parents in both groups reported having difficulty sleeping or letting go of worries. They reported changes in their marriage - more intense feelings of intimacy as well as more tensions."[99] There were some findings, however, specific to parents with a handicapped child. "Parents with developmentally disabled child,. however, expressed feelings about their child that suggested hopelessness, anger or rejection."[100] Also, "parents of developmentally disabled children evaluated themselves as changed in more negative ways since the baby's birth than did parents of nonhandicapped children."[101] Gath matched 30 families with a newborn mongol baby with 30 families with normal babies. These families were followed for 18 months to 2 years. The researcher concluded that, "The effect on the maternal health of a woman having a mongol baby is similar in type and degree to that experienced by other women bringing up small children in difficult circumstances, and not significantly greater than the effect of having a healthy baby."[102,103]

2. The Effects on the Marital Relationship

Another major area of interest seen in the literature is the effect that living with a handicapped child has on the relationship between his parents. Incidents in which parents quarreled and marriages fell apart ave cited. Positive effects on the relationship are also noted; the impression being that the presence of a handicapped child can sometimes "bring the parents together." Concern is often expressed for the special need for controls when investigating this subject. It is not enough to indicate that separation, divorce, etc. exist in homes where a handicapped child is living; the cogent question becomes, rather, whether the rates found are significantly higher than that of the general population. A specific interest in the effects on the marriage was found on the part of researchers in the field of spina bifida. Articles dealing with this will be discussed in a separate section below.

The general trend of the research findings in this area appears to be that the differing effects seen depend upon the pre-existing marital relationship. If the marriage had been a good, established one, living with a handicapped child could be weathered or could even strengthen the marriage. If, on the other hand the relationship was shaky and of short duration, the strains involved might shatter it.

A number of authors relate to the effects on the marriage of living with a handicapped child, when considering the general implications of a variety of handicapping conditions. Mandelbaum and Wheeler's observations were based on cases studied at the Children's Service of the Menninger Clinic, which included children with a variety of defects, many of whom were defective to such a degree that they were disturbed in most areas of functioning. The authors found that "quite often disagreements about a child and his potentialities spread throughout the marriage and threaten total disintegration of the family. In such cases, it is difficult to determine whether the child is the major cause of marital tension, and if so, whether the parents have enough stability and find sufficient gratification in other areas of their relationship to indicate possibilities for saving the marriage."[104]

Barsch's investigation of child rearing of the handicapped child, in which a wide variety of handicapping conditions was explored, cites findings which strengthen the view that the degree of marital discord depends upon the existing marital relationship. In exploring disagreements between the parents, Barsch found that,

> "As a general rule the mothers and fathers were in agreement on their responses to questions about child-rearing practices. Minor disagreements were noted on some points in the protocols of all couples who were interviewed but such disagreements were not on significant issues. Where the extent of disagreement was significant, the response patterns of both parties gave indication that the marriage was poorly integrated and that daily living had become a succession of open arguments or a matter of quiet hostility in which both were mechanically going about the business of day-by-day living. Such cases were in the minority."[105]

He further concludes,

> "The data obtained do not suggest that marital difficulties could be attributed to the presence of the handicapped child in the family. Rather, the day-to-day adjustments to integrating the child into the family could be viewed as a stress factor which served to aggravate a basic problem of discord within either or both parents."[106]

Drotar et al, exploring the adaptation of parents to the birth of an infant with a congenital malformation, studied the parents of 20 children with a wide range of malformations including mongoloidism and congenital heart disease. He found that, the "crisis of the baby's birth had the potential of bringing parents closer together, or birth estranged parents from one another. The ongoing demands imposed by the baby's care increased isolation between parents - particularly if they did not share responsibilities."[107]

The evidence from studies focusing on families with children who are mentally retarded leads to similar conclusion as to effects on the marital relationship. In Holt's sample of 201 families, he found 12 in which "the parents quarreled with each other severely, frequently and persistently, and this marked unrest appeared to be directly attributable to the presence of the handicapped child. Quarreling occurred from time to time in varying degrees in other families, but this was particularly serious in the 12 families."[108] He proposes three main reasons for this unrest: 1) the mother's, and less often the father's, extreme exhaustion, 2) the mother's extreme devotion to the child with the rejection of her husband, 3) the fear of further pregnancies. Ten families were found in which the parents had separated, although in only two of these could the separation be traced directly to the presence of the handicapped child. It was felt that a number of these would have probably broken up in any case. Holt summarized his findings on this subject as follows: "It seemed then, that the mother's devotion to the child, with the consequent neglect of the family, was the most potent factor in causing unrest in the home, and separation of the parents in a few cases. In most families of reasonable integrity, the burdens were shouldered, even though this led to quarreling, and only in the less secure families was separation observed."[109]

Gath, in her study of the impact of an abnormal child on the parents, included a consideration of the effects on the marital relationship. Her investigation involved 30 families with a newborn mongol baby being matched with 30 families with a normal baby. Both groups were followed for 18 months to 2 years. Gath describes how she found a number of marked differences in the quality of the marital relationship between the two groups: "While there were no major upheavals in the control families, one marriage in the mongol group had already ended in divorce and another in permanent separation. The difference in quality of the marital relationship applied also to those couples who stayed together, as six of the couples with a mongol baby showed severe tension, high hostility, or marked lack of warmth between husband and wife. No couple with a normal baby had problems as serious as these, though a few had moderate difficulties in their married lives."[110]

She points out, however, in speaking of the percentage of parents with relationships rated as good that "Yet, on the other hand, half of the marriages of the parents of mongols were rated as good, meaning that they were characterized by mutual concern and affection, and this was near the number of good marriages in the control group."[111] She thus asserts, "All negative measures of the marital relationships were higher in the mongol groups of parents, but positive measures were also higher in the mongol group. Despite their grief, the parents of almost half the mongol children in this study felt drawn closer together and their marriage strengthened rather than weakened by their shared tragedy."[112] Her book, published a year later, apparently went into this aspect in some detail.[113] One reviewer found the most ominous finding of the book to be that "in the marriages of couples with Down's Syndrome babies, they were significantly more likely to be unhappy one year after the birth. The abnormal child's birth appears to magnify pre-existing weaknesses, turning stresses into obvious rifts."[114] A second reviewer, indicates that Gath summarized her findings, in a formulation that seems to mirror the consensus on this issue, as follows: "There was no evidence that the birth of a Down's Syndrome baby caused discord in a happy marriage, but it did have potential to disrupt the balance of a moderate or more vulnerable marriage."[115]

Pillig, reviewing the literature on the effect of having a mentally retarded child on the marriage, comes to a similar conclusion: "there is no one way in which marriages are affected by there being a subnormal child. Some marriages are unaffected, in others the parents are drawn closer together, while a few are disrupted. It seems likely that the birth of a subnormal child leads to severe disturbance for the marital relationship, or separation most often when there are previously existing tension. In some cases the child's birth is a unique stress, but in most the child is only one of many causes of marital difficulty."[116]

Pillig discusses the work of Farber in this context. Farber explored a number of factors that might potentially influence the effect of the child on the marriage. As Pillig describes his findings, "He found that boys had more adverse effects than girls, particularly when they are older. The difference between the sexes was much greater for lower-class than middle class parents. He suggests that this is because lower-class boys are expected to achieve more than girls outside the home. In the middle-class there is also an emphasis on the girls' career and so the sex difference is reduced."[117] She continues, "Farber also found that where wives spent a considerable amount of time with neighbors or husbands in formal organizations marriage problems tended to accur. He suggests that ordinarily such relationships give support to family life. Their values might be inappropriate, though, for parents of a subnormal child and provide an escape from their problems and responsibilities."[118]

Farber also explored the effects of other relationships, finding that when the parents of a retarded child were in frequent contact with the wife's mother, marital integration tended to be high. When they are in frequent contact with the husband's mother - marital integration tended to be low. As an explanation, he suggests that "Ordinarily, the wife's mother showed much sympathy and understanding for her daughter's situation, but the husband's mother generally blamed the wife for the retarded child. Sometimes there was an implication that the mother-in-law regarded the retarded child as punishment for her daughter-in-law's wrongdoing.[119] Pillig mentions that Farber also found frequent contacts with the Catholic church to have a favorable effect on marriage. She makes a salient point, however, when she asserts that, "these findings of Farber's provide many hypotheses that meed to be tested on other samples before their general validity can be determined."[120]

As part of her detailed consideration of this issue, Pillig points out a study indicating that the availability of services may affect the quality of the marital relationship of parents with a subnormal child at home. Fowle's study is mentioned in this regard, in which mothers in the sample had children who attended community day care. The mothers are described as having had some relief and were considered to, therefore, be better able to realize their potential as wives and mothers.[121]

In terms of the literature on the physically handicapped child that pertains to the effects on the marital relationship, the special interest shown in regards to spina bifida children has been mentioned. These studies will be discussed below. McMichael's study of 50 families of children with physical handicaps also included findings on this issue.There was no control group in this research. Marital disruption was found in a number of families, as described by McMichael: in "9 families, 18%, one or both parents had deserted the handicapped child, in 6 permanently and in three temporarily. Five of these ended in divorce, leaving 3 mothers and 1 father to bring up the child alone".[122] When parents were asked how the child had affected the marriage relationship, 10 of the mothers answered that it had improved it, 33 that it had no effect, 6 that it had made it worse, and 1 not applicable. Further description of this is given: "the ten mothers who said 'improved it' typically made a comment such as 'has drawn us closer together - sharing each other's anxiety.' Of the 33 who said 'no effect', 4 implied 'it couldn't be worse.' Of the six who said 'made it worse' two fathers had deserted, and the other couples were having marital difficulties. One father had left home temporarily, one was on permanent night-shift and in one case the mother said she would have left her husband if she hadn't felt a broken home would be bad for the child."[123] McMichael presents findings which suggest that the child's prognosis can affect the marital relationship, especially when the prognosis is grim. She reports that "The greatest emotional difficulties are likely to occur in those cases where the parents are told that their children will be unlikely to survive adolescence. In nearly half (7) of the cases in this category in the sample studies, marital relations were strained almost to breaking point, and in two of them there had been temporary separation."[124]

a. The Marital Relationship of Parents of a Child with Spina Bifida

A special concern with the effects on the marriage of having a child with spina bifida is evidenced in the literature. At least seven articles are available which deal with this, a number of them focusing exclusively on this issue. The evidence from this literature is somewhat conflicting. Most of the relevant studies found a rate of separation or divorce that was not significantly higher than that of the general population. Two studies however, did find a significantly higher rate.

The results of a number of these studies support the general trend in this area as described in the section above; the quality of the marital relationship before the birth greatly determines subsequent effects on the marriage. A number of articles point out that the severity of the child's handicap was not found to be a factor influencing the quality of the marital relationship.

Four British studies are known; the results of three of these agree as to conclusions drawn, the results of the fourth are in the opposite direction. Walker's study of 107 children with spina bifida children indicates that, for the majority of parents, the marital relationship is not affected by the birth of the baby. Mothers and father were queried separately as to this. Twelve mothers responded that the marriage had improved, 66 that it stayed the same, and 28 that it had deteriorated. The pattern of response of the fathers was similar; 12 stated that the marital relationship had improved, 59 that it had stayed the same, and 15 that it had deteriorated. Thus, only a total of 43 parents, out of 192 responding, thought that their relationships had deteriorated. There was, however, some indication that tension had increased in the house since the birth, with 77 mothers, and 56 fathers affirming this to be the case.[125]

Freeston, interviewing 85 parents of children with spina bifida, found 3 instances of complete breakdown of marriage following birth of the handicapped child. He concludes that this rate is not higher than that of the general population.[126] Dorner, studying the parents of 63 adolescents with spina bifida, concluded that "marital harmony or breakdown did not occur more frequently than in the general population." He also notes that there was "no association between poor marital relations and severity of handicap."[127]

The research of Tew et al present some compelling evidence for the opposite conclusion; that the presence of a spina bifida child does adversely affect marital relationships. This study was carried out on a sample of 59 index and 58 control families, in which contact was maintained for 8 to 10 years. Marital harmony was assessed, using a five point scale. after the birth of the child and again 8 to 9 years later. It was found that "at the time of the birth, 70% of both index and control parents seemed to have a satisfactory relationship, but slightly more control parents had slight to severe difficulties in their marriage. By the time the child was nine years old, only 46 per cent of the index parents had satisfactory relationships, while in the controls this had improved to 79 per cent."[128] This difference was found to be highly significant. In explaining in greater detail, the authors point out that, "In the index families the 16 marriages rated as less than satisfactory at the time of the child's birth were much more likely to have deteriorated than to have improved: 3 which had had difficulties were now satisfactory, two had remained unchanged, but 11 had deteriorated further. This compared with only five of the control marriages which had deteriorated."[129] The severity of the child's handicap was not found to influence the quality of the marital relationship.

The researchers also examined the differences in divorce rate between the two groups. They found that 7 divorces had occurred in the index parents, a rate of 13.2 per 1000 marriages. Three divorces occurred among the control group couples, a rate of 5.7 per annum. The authors cite a national (British) average of 7.1 per annum, and so conclude that the divorce rate of the index families was more than twice that of the controls, and almost twice that of the national average. Couples who were younger and had been married for a shorter period of time were found to be more likely to separate. Also, couples where the child was conceived before marriage were in much greater danger of separation. They sum up their findings "the quality of the marital relationship in the index families was found to have deteriorated over the years, but to have improved slightly in the control families...Only one in four of the index families appeared to be free of marital difficulty."[130]

The authors are aware that "this study presents a gloomier picture of marital relationships following the birth of a handicapped child than do other studies." They feel that the high degree of family disruption found in the study is probably attributable to: a) the longitudinal nature of the inquiry, carried out by one person who knows each family well, and b) the fact that the children in the study are older than in other studies. Tew and Lawrence conclude that "The birth of a child with spina bifida seems to present a serious challenge to the stability of a matrimonial relationship, though in spite of the stresses involved, one quarter of the marriages in this study appear to be unaffected. The results of the study confirm that more often than not the family of a handicapped child is a handicapped family."[131]

The two American studies which explore this point similarly differ as to results. The first of these indicates a high degree of marital disruption in families with spina bifida. The findings of the second study, designed to specifically test the results of the first, do not support such a conclusion. The initial study, that of Kolin et al, followed all known children born between 1957 and 1961 at New York Hospital. The resulting sample was composed of 13 children, between 7 and 11 years old. Parental adaptation was examined, in terms of four areas; understanding of defect, role in child's development, marital status, and mental status. Good parental adaptation was found in 3 cases, fair in 2, and poor in 8. Six of the marriages were no longer intact, a marital breakdown rate of 6/13, or 46%. The degree of physical impairment was not found to be a factor determining parental adaptation. Indicating factors which did effect adaptation, the researchers assert that, "only the parents who had the opportunity to develop a stable relationship over a minimum of 5 years of marriage were able to cope successfully with the crisis presented by a defective child."[132] They also point out that, "the intact marriages had at least one normal child prior to the birth of the patient. Those who had planned the pregnancy, suggesting high emotional investment in the child, achieved a better level of adaptation than did parents to whom the pregnancy was unexpected."[133]

Martin, testing the hypothesis that a relationship exists between marital disruption and the presence in the family of a child with spina bifida cystica, studied 34 mothers or guardians of such children. This was the second study found which was carried out in the U.S. Martin selected two comparison groups; 59 mothers of relatively healthy children with minor illnesses (sore throats, colds, infections) who attended Walk In or Continuous Care Clinics in the hospital, and 60 mothers of children with juvenile-onset diabetes. The first comparison group was considered to be "as close to the general population as any group selected from a hospital population could be." The author's rationale for the second comparison group is not clear. Martin found that "a) the over-all divorce/separation rate in parents of children with spina bifida cystica is not statistically significantly higher than in the general population. b) the parents whose marriages broke up reported that in 75 per cent of cases the marriage was previously strained. The handicapped child in most instances added to the existing stress. c) In contrast, parents who did not divorce or separate generally reported that the affected child had brought them closer together."[134] She specifically adds that "the high divorce rate in the New York population studies by Kolin et al is not supported in the present study, and the factors (stable marriage prior to the birth, planned pregnancy, other normal children) they thought important in parental adaptation to a child with spina bifida are not confirmed."[135]

3. Effects on Sex and Reproduction

There has been some interest some in the literature on the effects of having a handicapped child on the sexual relationship between the parents, and, especially, their desire for more children. Kew discusses the former aspect. He states that for men, the birth of a handicapped child places a question on their virility, especially if it is the first child. Women are described as feeling "bad inside". With such feelings present, asserts Kew, it is not hard for the sexual relationship of the parents to deteriorate.[136]

A number of articles lead support to the idea that the presence of a handicapped child becomes a factor in the parents' consideration of having additional children. It appears that for most couples, this exerts a negative influence, with parents feeling that they don't want additional children. The major reason for this being the fear of having another handicapped child, and the feeling that they couldn't cope with additional responsibilities on top of the demands involved in the care of the handicapped child. For a smaller number of parents, it appears, having a handicapped child becomes a positive factor in the choice to have more children. Couples are said to want to thereby prove to themselves that they can have a normal child, to provide companionship for the handicapped child or for a normal sibling, or to better ensure that the handicapped child continue to have family members concerned for his welfare. Some factors postulated as being elements in this decision are age of mother, birth order of the handicapped child, severity of handicap and adaptation of parents to the handicap. One factor that, oddly enough, does not appear to be seriously considered by researchers in this respect, is whether or not the handicap has a genetic basis, so that future births involve an element of real risk.

In the Carnegie survey of mentally retarded children in Glasgow, researchers found that in "19 of the 39 families in this group, efforts had been made to avoid having further children, sometimes because it was felt that the family was large enough already, sometimes because of the presence of the handicapped child - because of fear that another child might be handicapped, or simply from inability to cope with a new baby in addition to the handicapped child already present in the family."[137]

Tizard and Grad, in their sample of London families of mentally retarded children, are described as also finding a tendency to avoid having additional children. In their studies, however, there was a very small percent of families in which other children were conceived to compensate for the disappointment over the defective child.[138]

Mandelbaum and Wheeler, discussing families of defective children, present similar results. "Some mothers try to deal with their distress by not having other children. Others want another child, hoping that they can prove their adequacy and their capacity to bear healthy children."[139] Barsch, in his study of the child-rearing practices of parents of handicapped children with a variety of handicaps, asked parents whether the handicapped child had anything to do with their desire to have more children. He found that while most of the parents commented that this did not influence them, there were a number who freely expressed that they limited their families, or that they deliberately sought a subsequent pregnancy. They found age of mother and severity of handicap to interact in such a way that "an older mother with a severely handicapped child will be more likely to limit family growth subsequent to the birth of a handicapped child than would a younger mother with a moderately handicapped child."[140] This study points out that the stated desire and the actual consequences were not identical in all cases. Some mothers had stated emphatically that they wanted no more children, but, in fact, did have one or several children subsequent to the birth of the handicapped child.

Kolin et al studying the adaptation of parents to spina bifida children, found the desire for an additional child to be more intense in the better-adapted parents.[141] McMichael, in her research on the families of physically handicapped children, found that, "The fear of future pregnancies, including the fear of having another handicapped child and the burden of trying to look after younger children in addition to the handicapped child, especially where the handicap was severe, was almost universal."[142] She reports that "approximately 80% of the mothers of children with congenital handicaps expressed their fears of further pregnancies." Out of the sample of 50 mothers, four had been sterilized, 2 in direct relation to the handicap.

Holt carried out a study which focused specifically on this issue, "The Influence of a Retarded Child Upon Family Limitation," and surveyed 201 families with a mentally retarded child at home. Holt calculated that 34 fewer children were born than would have been otherwise, in the 160 families in his sample in which further pregnancies were possible after the birth of the retarded child. In 90 (56%) of the families, the parents did not want any other child for reasons directly related to the retarded child. Thirty-three of these feared that another child might be similarly affected, and 57 felt that the defective child required too much work, or because the mother wished to give the defective child all her attention. In 11 families more children would not have been wanted anyway and it was felt that the presence of the defective child did not appreciably affect the decision. Thirty-nine (24%) families wanted more children; 7 of these felt this way after they were satisfied that there was little chance of having another retarded child, 4 specifically wanted more children to help with the retarded child's development. In later follow-up, it was found that 29 of these families wanting more children had at least one successfully. The remaining 20 families were considered to be problem families, indiffenent to the question.[143]

B. Econimic Effects

1. Financial Outlay

One of the areas in which the family with a handicapped child appears to be affected is financial. There are specific needs and conditions associated with having a handicapped child that give rise to financial outlay beyond which families with normal children would be expected to experience. Sources of expense in this respect that are mentioned by researchers include special clothes, shoes, and equipment, replacing quickly worn-out clothes, bedding and equipment, special food, medicine, traveling expenses, installation of telephone, moving or adapting house, and continued costs for board and lodging of adult children. As the studies involved did not include control groups, the extent to which these costs are beyond those incurred in raising normal children was not determined.

Holt, in his study of 201 families of severely retarded children, found expense to be the second most frequently cited problem area, after "constant supervision". Fifty-nine parents, 29% complained about expenses incurred in the care of their children. Holt grouped the causes of extra expenses in five categories: 23 of the families incurred expenses in seeking advice or training for the child in the hope that it would be beneficial, 20 cited "damage", 9 felt worn out clothing because of roughness or frequent soiling to be the source of extra expense, 5 cited traveling expenses, and 2, alterations to the house.[144]

Tizard and Grad mentioned similar sources of financial outlay for the parents of the mentally retarded. They found that money might be needed for special food, medicine, replacements for destroyed clothes and bedding, and for traveling to clinic. They also judged only 35% of their home sample as having a 'good income', while 25% was rated as poor. They point out that the mothers were unable to supplement the family income by working, or were only able to work part time, because their presence was needed at home.[145] The Carnegie study of mentally retarded children in Glasgow found that "many of the children damaged clothes and sheets by tearing them and biting them so that extra repairs to furnishings and extra shoe repairs became necessary; their clothes could not be 'handed down' to younger children. Since many of the mother would have been out at work if the child had been normal, this extra wear and tear represented an additional hardship to them under the circumstances where financial conditions were often already severe strained."[146]

Begab, reports on the costs of raising mentally retarded children. He adds an additional dimension of the long-term nature of the support provided by parents of the retarded, as distinct from that provided by parents of normal children. "The care of children with associated physical defects and continuing medical needs is a severe financial drain. Extra costs are involved in seeking medical advice and treatment for some, and training and recreational opportunities for others. Even the cost of board and lodging, from which parents of normal children usually obtain relief when the children are grown, may continue indefinitely. Not uncommonly, the depletion of the family's resources may have far-reaching consequences on its mobility, earning power, and educational level."[147]

The literature on physically handicapped children indicates similar areas of financial outlay. There is, however, in addition, a special emphasis on the expenses incurred when the child is hospitalized, as for many of these children repeated hospitalization appears to be the norm. Kew asserts that "the family as an economic unit is affected by handicapped much more than has been generally appreciated." He points to expenses incurred by travelling to and from hospital, taxi-fares, installation of telephone, special clothes, adaptation in the home and moving house.[148] Richards and McIntosh in their study of 86 families with a child with spina bifida, found moderate degree of financial hardship in 49 families. Specific expenses were incurred as clothing and prams wore out quickly, and the cost of shoes was noted to be a problem. Some parents were found to be unable to visit their children, while they were in hospital, as they would like because of expense. Twenty-four of the mothers went to work to augment income on account of the handicapped child.[149] McMichael, writing about 50 families with physically handicapped children, noted that "hospital visiting over a long period, can prove a costly item in the family budget when it includes fares, the inevitable small presents for the child, and perhaps a payment for for the other children who have to be left at home. The cost and repair of special boots and shoes can also be heavy on the family purse."[150]

2. Social Mobility

Farber has indicated interest in the associated question of how the presence of a severely mentally retarded child in the family affects the long-run social destinies of other family members. He cites a study done by Culver who investigated social mobility patterns of parents of severely mentally retarded children. This researcher compared the fathers' occupations with those of the child's grandparents. The study utilized data collected in Chicago on approximately 400 families with severely mentally retarded children living either at home or in an institution. Farber reports this investigation as showing that the timing of the birth of the mentally retarded child was related to the upward or downward social mobility of the parents. The earlier in the marriage the child was born, the greater were the chances of his having a depressing effect on social mobility. Thus, when a couple had a retarded child early in their marriage, the husband's chances of moving upward occupationally were impeded. Moreover, among families in which the grandfathers of the retarded child had white-collar occupations, the parents who kept their severely retarded child at home were more often downwardly socially mobile than were those who institutionalized their retarded child.[151]

Farber refers to a study in which he described three theoretical types of family organization developed by parents, of retarded children, which differ in terms of effects expected on their social mobility. These he calls "parent-oriented", "child-oriented", and "home-oriented". The parent-oriented families he describes as focusing on the father's and mother's occupational and social careers, and as assigning to the retarded child a secondary position in determining the life chances of family members. Husband and wife consider themselves as colleagues in a family enterprise.

The child-oriented families are seen as subordinating the relationship between the parents in order to maximize the life chances of their children. The division of labor in this group of families is described as being such that the husband would specialize in work activities (sometimes to the exclusion of other activities) while the wife cared for the home and family. Here again, great expenditure of time and effort is seen as compensating for the depressing effect of the retarded child on their upward social mobility. In the home-oriented families, parents are seen as completely sacrificing their life chances for family cohesion. The husband is described as disregarding his personal career in order to maintain family unity; and consequently the life chances of all the members are seen as possibly being markedly affected. However, Farber remarks, that "there was a large proportion of families in the investigation who did not present a clear-cut type of orientation. There was considerable disagreement between the parents with regard to orientation, and in many instances the orientation itself was not crystallized."[152] Farber felt that families in this residual category were probably most affected in their life chances by the retarded child. He suggests that "perhaps the numerous problems that had beset them interfered with any concerted effort to promote upward mobility."

3. Parents Work and Career

a) Mothers

There exists some comformation in the literature for the hypothesis that having a handicapped child is an influence on the parents' especially the mothers' work and career. Although this has not been found to be a primary focus of empirical research, it is mentioned by a number of authors, with one study finding work to be an important factor in level of stress of mothers. Having a handicapped child in the home, is seen as having possible effects on the mother's decision to work in two different directions. The additional expenses involved may force the mother to go out and work. Most observers, however, seem to feel that the influence tends to be in the opposite direction. Mothers who would otherwise be out at work, must stay at home to care for the handicapped child.

Richard, and McIntoch, in their study of 86 families of children with spina bifida, mention that 24 of the mothers went out to work to augment income.[153] Findings from a number of other studies indicate an opposite effect. Tizard and Grad found that, "mothers were unable to supplement the family income by working, or were only able to work part-time, because their presence was needed at home."[154] The Carnegie study depicts homes in which financial conditions are severely strained, more so than if there had been only normal children in the family, "since many of the mothers would haave been out to work if the child had been normal."[155]

Farber, in his discussion of the limitation on participation of parents of severely retarded children in extra-family relationships, mentions two studies referring directly to work. He cites Hall, in research on cerebral palsy children, as finding that mothers of the more severely handicapped are more likely to remain in the home than to take outside employment. Similarly, Meyerowitz and Kaplan's findings that mothers of children with cystic fibrosis often ceased outside employment is mentioned in this regard.[156]

Limitation of involvement in outside work when a handicapped child is in the home has been felt to have potentially serious implications for mothers who view work and career as integral parts of their lives. Greenberg, cited by Wolfensberger, mentions the social changes in parent coping with handicapped child that have occurred with time. He suggests that, in the past, families were bigger and parents could displace hopes and investment to other children. Now, he feels, the handicapped child is more likely to constitute a threat to mother's career aspirations and may be resented.[157] Kew points out that mothers "who are particularly identified with their professional and social roles frequently feel that these are incompatible with their newly acquired role of mother and nurse to a permanently disabled child. In such cases, the crisis can only be resolved by radically modifying, or perhaps even abandoning one or the other of these roles. Many women in this situation will look for a solution in placing the child in residential care, although others will abandon outside commitments and turn their energies inward in an affirmation of their family roles."[158]

That such limitation or abandonment of work role has negative consequences for the mother's mental health is indicated by Bradshaw and Lawton's study of stress in families with severely handicapped children. The level of stress, as measured by a malaise inventory, was found to be extremely high in the 303 mothers in the sample. The researchers sought to determine factors that varied with stress. A major finding of the study was that the level of stress experienced by mothers varied with according to their satisfaction or dissatisfaction with their roles as housewife or worker. (This finding becomes especially significant when the factors that did not relate to stress, surprising even to the researchers, are kept in mind. These include degree of child's particular disease, his degree of handicap, the child's age, mother's age, and standard of housing.) The mothers with the highest stress scores were those who were not able to work but wanted to. The mean for this group was a very high 10.32. (In understanding this score, it should be kept in mind that, according to the authors, scores over 5 or 6 are outside the normal ranges and show evidence of disturbance. The mean scores of the whole sample was 9.02) The next highest mean score, 8.64, was for those mothers who stayed home and did not want to do paid work. Those mothers who were able to do paid work unrestricted had the lowest stress score. The mean of this group was 6.26, a score just slightly elevated beyond that considered normal. The authors point out that, "the variations between these groups of mothers were the largest observed in the analysis, and it is interesting to note that only 27.5% of mothers in this sample had paid work compared with 40.7% of the population of all mothers with dependent children."[159]

b) Fathers

Effects of the father's work and career have also been mentioned in the literature. Both restrictions of work, and better involvement in work have been reported in this context, with the additional suggestion that intense preoccupation with work may serve the function of limiting their father's involvement in the home.

Holt found that in 6 out of his sample of 201 families of severely mentally retarded children, the presence of the retarded child affected the father's work. The father was described as being unable to do his work, and as not feeling able to take opportunities for advancement.[160] Kew, referring to the fact that family income from employment is often altered when a handicapped child is present, cites a study by Schonell and Watts, in which 26% of fathers are described as finding it necessary to alter their careers.[161]

A number of observers describe the fathers as becoming more involved in work, as a way to further remove themselves from the, presumably difficult, situation at home.

Barsch, considering the role of fathers in the care of their handicapped children, found that, "Most fathers do not become engrossed in the suffering process, associated with the initial concern and progressive awareness. They seem to adopt a little boy or brother role in relation to the problem, and conveyed the idea that they were removed from the situation - not by choice, but by circumstances... Many plunged themselves into intensive preoccupation with the business of making a living."[162] Meyerowitz and Kaplan reported that fathers of children with cystic fibrosis "might take on a second job and limit their activities as husbands and fathers."[163] Howell, presents similar observations: "In some instances fathers may hold two or more jobs, ostensibly to finance care for the handicapped child. This is used as a rationale by the father, the covert reason is that life with his family is just not tolerable. The father prefers to be away from home, to leave care of the handicapped child to his wife."[164]

C. The Effect on Family's Relationship to the Outside Community

1. Social Life and Leisure

It has been discussed by a number of observers of the family with a handicapped child that these families are restricted in their relationship with the outside community. A tendency for these families to remain at home has been noted, due to the need to care for the handicapped child, and the attitudes of the family members. Membership in community organization, visits with friends and relatives, both within and outside of the home, as well as an evening out for leisure by the parents have all been cited as being curtailed in these families. A number of researchers have been found to assert that, rather than the presence of the handicapped child being the factor limiting interaction with the community, it is the specific personalities of the parents that determine their participation in outside activities. Some people are described as being "joiners" and others "loners", whether or not they have a handicapped child. Attitude, rather than actual frequency of going out, is also cited as a factor in parents' feeling of isolation

Farber asserts that "One of the most consistent research findings is the limitation on participation of parents of severely retarded children in extra-family relationships, such as organizational membership or recreation."[165] He discusses pertinent findings from a number of studies, including those of Schonell et al in Australia who found that "about half of the families reported that their visits to other people's homes and their shopping arrangements were affected" and that, "parents also found it impossible to indulge in daily social activities." Tizard and Grad are also mentioned in this context, reporting that, "about half of their families with a retarded individual living at home reported that their social contacts were limited by the presence of the child."[166] Farber asserts that "other investigators report a similar pattern" and concludes that "taken together, the findings of the various studies concerned with the extent of community relationships suggest that the families of severely handicapped children tend to disengage themselves from these activities and to focus attention on problems within the family."[167]

Kew, in his discussion of the "change in relationship between family and community" for families of handicapped children indicates that "research points out that because of exceptional care problems associated with many handicapped children, parents are often tied to homes. This tends to isolate them from friends and sometimes leads to deep feelings of loneliness."[168] He points out that this can be exacerbated by shame in "display" of a handicapped child in public, although he feels that most parents seem to overcome these feelings. Kew refers to the findings of a number of studies, noted to be the same ones mentioned by Farber, as evidence of this isolation from community activities. He also, however, discusses Hewett's findings which indicate that "handicapped child families seemed able to cope as well as any other.": "It seemed that feelings of isolation were much more a function of the mother's personality than of the presence of the handicapped child."[169] According to Kew, however, Hewett did feel that the "plight of mothers who are lonely and feel cut off is very real" and that this is "more likely to happen in rural areas where problems of transport and finding friends in similar situations is very great."[170] Kew concludes his consideration of this subject by saying that the "family's relationship to the wider community undergoes considerable stress and change. For families who are socially aspiring, this can result in an unbearable situation."[171]

Two studies of children with physical disabilities point to the isolation of their families. Walker et al studied 107 families of children with spina bifida. One of the impacts on family life was found to be isolation, with 73 out of 106 mothers, (69%), feeling isolated as a result of the child, and 41 out of 91 couples not having been out socially since the baby's birth.[172] McMichael, in her study of 50 families with severely physically handicapped children, asked parents whether their leisure activities were restricted in any way; that is, if they were different from what they would have been were the child normal. Twenty-eight of the parents felt that their activities were 'not restricted', 12 said thay they were 'severely restricted' and 9 included the handicapped child in their activities but found him a 'tie'. The author points out that "thus over a third of the parents, 42%, reported that their leisure activities were severely restricted or that they found the child 'a tie'." This proportion, she sees as possibly being an underestimate, as some of the mothers may have been unwilling to admit how much the handicapped child restricted their activities.[173] When she asked the more objective question, "How often does the mother go out for pleasure, without the child?" she found that almost half the mothers, 46%, never did so, and another 24% went out less than once a month. In regard to the father, 28% did not go out for pleasure without the child, but over half, 56%, went out at least once a week. The availability of a suitable babysitter is cited as a possible factor in going out. Nine mothers are described as suggesting spontaneously that if they could get a trained sitter for their handicapped child, it would enable them to go out occasionally with their husbands. McMichael points out that attitude towards going out is important, and not just actual frequency of going out, in contributing to feelings of isolation. She notes that 18 of the mothers who never went out were not those who said that their leisure was restricted; they maintained that they would not have gone out in any case.[174]

The most common complaint of parents surveyed in Holt's study of 201 families with a severely retarded child, was that they could never go out together. Eighty-two couples, 41%, cited this as a problem. The only way in which a mother was able to have a break from child care, was if her husband took over. Thus, they never went out together. Some mother never left the defective child. This was found to be especially true for those children needing nursing care; 6 out of the 14 mothers of such children had stayed constantly with the child for several years. However, Holt asserted that "Apart from the group of children needing nursing care, the severity of the retarded child's condition did not always appear to be the most important factor affecting the ability of the parents to obtain relaxation. Whether the parents went out together in the evenings or not depended more upon their own wishes to do so, and their ability to have someone look after the children."[175] For 2/3 of the couples who went out occasionally, other children in the family babysat; most of the others relied on other relatives.

Holt found the attitude of the parents to be very important in terms of social isolation. He found such isolation to be a feature of more than half (126 out of 201) of the families. These parents mixed only with a small group of friends, were not eager to make new friendships, and had little wish to join communal activities. Holt felt that this isolation was not entirely due to the rejection of the family by the community, but that the parents' own desire to isolate themselves also played a part. Such isolation was observed in families with friendly and helpful neighbors and tended to persist after the child had been institutionalized.[176]

There are two researchers who indicate a much smaller percentage of families for whom isolation is a serious problem. Dorner, studying families with adolescent children with spina bifida found only 20% who found it difficult or impossible to lead a social life. Of the others, 57.5% of the parents were found to be able to lead a completely unrestricted social life, and 22.5% had to make special arrangements but were usually able to do so. A "close association between adolescent physical mobility and the social life of the parents" was found.[177]

Barsch completely denies that social isolation is a problem for the 177 families of children with a variety of handicaps he studied, and takes issue with other findings in regards to this. He cites personality differences, rather than the presence of a handicapped child, as making for differences in community participation. He asserts that, "In none of the cases was there any evidence that the parents had buried themselves into a social isolation as a result of having a handicapped child. Most of the parents held outside social interests, which regularly engaged their time and attention such as clubs, recreational activities, etc. Where this was not true of a particular parent the evidence did not suggest that the limitation of social activity held a significant relationship to the fact that the family contained a handicapped child. Some people are 'joiners' and some are 'loners'. In most cases the parents moved about freely in the community engaging in no shameful hiding of the fact that they had a handicapped child. They talked freely to neighbors and relatives about their child. While they made no particular effort to advertise this fact there was also no evidence of hiding. They took the child with them as they moved about the community and explained as was necessary."[178,179]

This aspect of attitude toward being active in the community as being important and not just the actual frequency of activity, is supported by the findings of Bradshaw and Lawton. Examining variables associated with stress in mothers of severely disabled children, they asked mothers whether they thought their leisure activities were restricted at all by their handicapped child. Mothers who described themselves as severely restricted were found to have higher stress scores than other mothers. Mothers were also asked how often they went out for pleasure. Stress was found not to vary with this variable, the actual number of times they were able to get out, but did vary according to their feelings towards this. Mothers who said they wanted to get out more than they actually did, scored higher than those who did not feel this.[180] It is apparently, a mother's feeling of being restricted and getting out less than she would like to, rather than the actual number of times she goes out, that has an association with the level of stress in her life.

a) The Too-Cohesive Family

Two researchers studying families with handicapped children found a number who focused exclusively on the needs of the handicapped member, and lived in almost total isolation from the outside community. This type of family organization they termed "too-cohesive."[181] Schaffer, studying 30 working-class families with young cerebral palsy children, found 13 families in which the members were rarely apart. All activities centered around the handicapped child and, for both parents, contacts with neighbors and friends, and leisure pursuits were practically non-existent. Other siblings were not regarded in their own right, but rather for the help they could give the handicapped child. The children in these families were no more severely handicapped than the rest of the sample, nor were family and neighbors more hostile. Schaffer notes that the unity of these families is precarious, and the removal of the handicapped child was likely to cause disruption.[182]

Tew et al in their investigations of families with a child with spina bifida, similarly found among the "families with an apparently satisfactory marriage there were 10 couples, all with a severely handicapped child, who could be described as 'too cohesive.' They exaggerate their parental role at the expense of their personal role and all activities are subordinated to the needs of the handicapped child."[183] These authors also point out that "because the families appear to be united, they may not elicit help from a social worker or a psychiatrist."

2. Vacations and Holidays

It has been noted in the literature that families with handicapped children may limit, or entirely cut out, vacations away from home. Two aspects associated with having a handicapped child in the family appear to contribute to this. The first is financial. If, as has been discussed, the financial outlay of a family with a handicapped child is substantially greater than that of other families, there may not be money available for vacation. Second, and perhaps more limiting in this respect, the difficulties involved in finding suitable accomodation and caring for a handicapped child away from home, may make a family holiday almost impossible to arrange. As these families may be seen as being in special need of a break in routine, and time away from home, such inability to take vacation may have unfortunate implications for the family's daily life.

McMichael, referring to families of physically handicapped children, mentions some of the families' concerns when considering possible vacations, "Problems of holidays and leisure facilities involve the whole family. Where can they take the handicapped child for a holiday - provided, of course, that they can afford one. 'It should be somewhere on the level not too far from the sea, with not too many people to stare at him and a landlord who won't mind wet beds.' Imagine trying to find such accomodation in the school holiday period - and the price of it."[184] She specifically asked her sample of 50 families about family holidays. Twenty-five stated that holidays were complicated by the child, 18 said that they have no holidays anyhow, 6 felt that the handicap makes accomodations difficult to find, and 17 cited financial difficulties.[185]

McMichael found that "many mothers referred to the difficulty of finding suitable holiday accomodation because of the severity of the handicap and thus the child's sensitivity towards strangers, or because of enuresis, incontinence, or the need for a wheelchair. The majority appeared to have found a caravan holiday the best solution. It was evident that the families, and especially the fathers, had to accept many limitations and restrictions on their holidays."[186]

In Holt's study, 34 out of the 201 families (17%) of severely mentally retarded children were reported to have the problem of "parents never taking a holiday." He states:

> "It was difficult for many of the parents to obtain the benefits of an annual holiday. For most of them a holiday meant the added strain of caring for the defective child in different and often strange surroundings. The parents in 34 families felt that the retarded child prevented them from taking holidays. Problems of travelling and the antisocial behavior of the children did in fact make holidays impossible for many of these families, but there were 11 families where holidays should have been possible if the parents had been able to bring themselves to make the effort. It appeared that in these cases, the holidays were prevented more by the parents' reactions than by the retarded child.[187]

Like McMichael, Holt found that for those families who did take a holiday, the type of holiday was affected by the handicap. "The majority of the parents who did take holidays preferred to go to cottages or caravans, or to stay with relatives, rather than to face the embarrassment of mixing with other people."

That the inability to take vacations is seen as a distressing effect of having a handicapped child by the families involved, was borne out at a conference on the "special child" held recently in Jerusalem.[188] In discussing some of their most pressing problems, parents pointed to this aspect, with one parent, in great distress, mentioned not having had a vacation in 15 years. The parents expressed anger in this regard. When partial solutions were suggested, such as arranging vacations for part of the family, with one parent staying home with the handicapped child while the rest of the family vacationed, these were rejected by the parents as missing the point; the need for the parents to be together on vacation. There was some interest expressed in the idea of providing care for the handicapped child overnight at his usual school, with his usual attendant, so that parents would be able to get away together.

The importance of vacations for parents of handicapped children, is indicated by a study of stress in such families, by Bradshaw and Lawton. These researchers administered a malaise inventory, a measure of stress, to 303 mothers of very severely disabled children. An extremely high average stress score, was found, higher than that of any other sample to which inventory had been administered. In attempting to account for variations in score, the researchers investigated a wide variety of conditions which they felt might account for this. Most of the variables investigated were found not to influence the stress of the mothers, including those related to the characteristics of the disabled child, or the social and economic circumstances of the family. Their finding, then, that whether the family had had a holiday recently did appear to be associated with the level of stress of the mother, appears especially significant. Mothers who had had a holiday during the last year were found to have significantly lower stress scores than those who had not had one for over three years.[189]

D. The Effect on the Siblings of the Handicapped

There is some interest evidenced in the literature on the effects of living with a handicapped family member, on the impact on siblings. As the focus of the present paper was seen as the effects on the family as a whole, and the parents in particular, a comprehensive review of literature relating to siblings will not be presented. There are, however, a number of issues raised in the literature surveyed of interest in this respect and these will be discussed.

There appear to be a number of aspects which should be included in a consideration of the effects on siblings of a handicapped individual. The first might focus on their lives as children, how their lives are affected during the time they live within a nuclear family with a handicapped sibling. The second might focus on their lives in a more general, or long term way; how their lives differ from those of people who have only normal siblings. For both of these aspects, comparison with control groups is clearly necessary in assessing the degree to which effects seen are actually caused by the presence of the handicapped siblings. Most of the research seen does not include control groups, rather, researchers report various behaviors seen in siblings of handicapped children. The degree to which the prevalence of these behaviors is different from that seen in siblings of normal children is, therefore, not known.

A number of researchers describe effects seen on siblings. McMichael assessed sibling adjustment in the 37 families in her sample of families of physically handicapped who had additional children. In twenty-four families, siblings were judged to show normal reactions towards the handicapped child, in five families a slight degree of failure to adjust was seen, in 4 a moderately severe degree, and in 4 a severe degree of failure to adjust was observed. McMichael thus points out that in 10 families, over 21%, siblings had a moderate or severe degree of failure to adjust.[190] She feels that "The main factors affecting sibling difficulties in emotional adjustment appeared to be the severity of the handicap, the extent of maternal anxiety, and the handicapped child's own emotional difficulties."[191] In Richards' sample of 86 families with spina bifida children, 76 had another child. Of these, 17 were found in which a diminished amount of attention giving was seen, which was judged to affect the siblings' behavior detrimentally. However, siblings were felt to be significantly deprived in only 6 families.[192] Tew and Lawrence, studying the brothers and sisters of patients with spina bifida, found the frequency of maladaption to be almost four times higher than in the siblings of normal control children.[193]

A number of studies point to the oldest female child in the family as being especially affected by the presence of the handicapped child. She may become a "second mother" in the family. Pillig describes Farber as finding that normal sisters, but not brothers had better adjustment after the retarded child was institutionalized. This he attributed to the daughter having to play the 'oldest child role' which involved responsibility for the siblings and tended to have adverse effects on personal adjustment.[194] Fowle's research is described as having similar findings. She is said to have found that the "role tension of the oldest female sibling in families with the mentally retarded at home was greater than that of siblings in which retardates were in residential care, and exceeded that of the oldest male siblings in the same groups."[195] Holt's research on the severely mentally retarded lead to similar observations. He did, however, indicate the role of the other siblings in providing help in the family. "In some families, especially in the working classes, the children were expected to help a great deal. It might be anticipated that an older sister would become a 'second mother', as was observed in 11 families; but almost as often, in 8 families, a boy had to do a large share of the work. Eleven children suffered seriously through this burden. The school teachers remarked that their work was very poor because they were always so tired, and one older boy lost a good post in a laboratory through his frequent absences looking after a defective sister."[196]

Holt also discusses the reactions of the other children in the families as having three aspects; resentment at the lack of attention they received, shame and embarrassment, and imitation of the defective.child. In terms of the first of these, Holt found that 20 of the children were extremely resentful of the attention given to the retarded child. This, he found, was most noticeable in older children. He notes that the rejection of the normal children for the sake of the defective ones could be very marked, and reports two cases in which mothers gave up normal children for adoption by relatives. Holt felt that the shame and embarrassment shown by the siblings was, to some extent, a measure of the parents own adjustment. These reactions were severe and affected the child's life in 10 cases. Imitation of the defective child by his normal sibling was found to be a serious problem in only one family.[197] Holt does report that 24 siblings, generally younger than the retarded child, had suffered physical attacks that were often unexpected, unreasonable and persistent. The victims of these attacks are described as being often reduced to a state of constant fear.[198]

Barsch's summary of his findings is in marked contrast to those described above, "The incidence of significant negative attitudes and behaviors from siblings in relation to the handicapped child is minimal according to these parents. The general picture presented by the parents is that siblings tend to accept the handicapped child and help in various ways...Parents in all groups perceived minimal evidence of adverse influence upon siblings."[199]

There are two literature reviews of the effect of the retarded child on his family, which consider effects on siblings. Wolfensberger, after considering the findings of a number of articles that related to this concludes that there is "no strong evidence presented that siblings of retarded have either a better or worse adjustment than comparable children in general." He finds "mild support for the view that youngsters will make an adequate adjustment and are apt to reflect parental values and conflicts."[200] Pillig, in a later review of the literature, found that, "much of the research in this area indicates that generally, there are few adverse effects on the siblings." She reports that "Where problems do arise it is generally because the siblings resent the amount of help they have to give, or the demands that the subnormal child makes on the mother's time."[201]

In terms of possible long-term effects on the lives of siblings of handicapped children,Farber suggests that choice of marriage partner could be affected. "Especially where the normal siblings have a close relationship with the retarded child, his presence may influence the choice of a marriage partner. Presumably, the siblings would not marry an individual who could not tolerate his or her retarded sibling...If the presence of a retarded child is highly disturbing to an upwardly mobile husband, the retarded child's sisters may reject marriages that would enhance their life chances."[202] It is also of interest in this respect to consider Pillig's description of studies by Tips and associates which show that fear of having an abnormal child may not only affect the parents of a retarded child, but also the brothers and sisters, who showed a marked drop in conceptions after the retarded child's birth.[203]

V. The Different Impact of Having a Handicapped Child on Different Families

A. Factors that Differentiate Impact

There has been some interest in tracing out the factors that differentiate the impact a handicapped child has on his family. Researchers have explored a number of demographic variables in this respect; SES, sex of child, religion, and family size. There does not appear to be an extensive body of research in this field. Such attempts to link independent variables which define the family to the particular impact likely to be effected,appear to be in a rudimentary stage. This is an area which could provide fertile grounds for future research.

Farber has been interested in the different impact of having a retarded child for different socioeconomic groups. A basic point in his theory is that the impact of having a mentally retarded child in the family, indeed the whole way the family deals with this situation, differs for different socioeconomic groups. Farber's hypothesis is that "the label of mentally retarded will have different consequences for family relationships to the extent that it represents a contrast to other labels." He thus proposes that "The higher the socioeconomic status of the family, the greater the impact on family relationships of labelling a child as mentally retarded." The discrepancy between the label "mentally retarded", and other labels ascribed to the family by society is seen as determining the degree of impact on the family. Thus, the label of mental retardation is expected, by Farber, to have less impact on family relationships in low socioeconomic families, because he considers that it is not greatly divergent from other labels associated with low status.[204]

Farber further hypothesizes that "The potency of child-care problems associated with mental retardation is related to SES status in effecting family relationships."[205] In high SES families, when the child is diagnosed as severely retarded, the discrepancy between his other labels and his intellectual label is sufficiently great to produce great emotional impact. If the child is educable retarded, the discrepancy is not so severe, and family relationships may not be as profoundly affected. For low SES families, however, since the label itself is presumably not the primarily crisis-evoking factor, child-care problems provide the basis for family tension. Regardless of the degree of retardation, if the physical disabilities do not require a great deal of effort and attention, the consequences for family relationships would not be severe at lower SES, suggests Farber.[206]

Farber makes a related distinction between SES groups in terms of the major crisis that mental retardation brings. He proposes two types of crises, tragic crisis and role-organization crisis. Tragic crisis refers more to the social context of family life, role-organization crisis with care problems. For middle-class mothers, asserts Farber, the major problems concern the frustration of aims and aspirations for themselves and their families. They see the retarded child as interfering with the attainment of certain ends in family life; they define the situation as tragic. Low economic status mothers are concerned with their inability to organize their domestic role in ways that permit them to have an acceptable family life; they are faced with a role-organization crisis. Thus, concludes Farber, "whether the crisis is defined as tragic or role-organizational seems to hinge upon the part played by the label of mental retardation in each SES group."[207,208]

Ehlers' study of 24 mothers of retarded children attempted to determine differences in coping with the retardate for different SES groups. Although his sample must be considered extremely small for this purpose, it was divided into 3 SES groups; lower-lower class, upper-lower class, and lower-middle class. Ehlers found mothers in the lowest SES group to be less likely to cope with their child, to talk over problems with their husbands, and to have a good marital relationship. Mothers in the upper-lower class,he considered to be more stable, more able to cope with the children, to have better marital relationships, and to talk more with their husbands.[209] Ehlers felt that his lower-middle class group "presented a distinct and solid pattern of reporting and being able to cope with their retardate."[210]

Farber also discusses the role of the sex of the retarded child in determining impact on the family. He cites a study by Talman which found that the father tended to be more highly motivated in coping with problems of retarded boys than girls. Farber also mentions a study he carried out with associates which found the initial stress on the parents to be somewhat sex-linked, with the mother indicating a slightly greater impact if the retarded child is a girl and the father, a markedly greater impact if the child is a boy. He reports further,"In low status families where sex differentiation in family roles is probably greatest, mothers suffered a much greater impact when the retarded child was a girl. With time, however, the mothers of retarded boys were confronted with more severe problems than mothers of retarded girls."[211] A finding has been mentioned in this regard, that retarded boys are more likely to be institutionalized than retarded girls.

The negative findings of Cummings et al, in regard to differentiation of effects on the mothers of retarded children, by the child's sex and age, are of interest in this regard. The researchers investigated selected personality features of the mothers and concluded that these mothers experience psychological stress. They then explored variables relating to the age and sex of the children. The researchers' original hypothesis had been that the mothers of older children would demonstrate higher levels of psychologically negative traits than the mothers of younger children, implying a cumulative stressful effect through time. Finding that neither the age nor the sex variables yielded clearly significant means, the authors conclude that their hypothesis is not supported.[212]

Investigating the role of religion in determining acceptance of a retarded child, Zuk found this to be a factor, with acceptance highest in Catholic,and lowest in Jewish, mothers. He describes Jewish mothers to be totally non-accepting, which he explains by noting that Jews place a particularly high value on intellect.[213] Kolin found religious feeling to be more intense in the better-adapted parents in his sample of families with school age children with meningomyelocele. This suggests perhaps, that degree of religious feeling may be a factor in adaption to handicap.[214]

Wolfensberger points out that the birth order of the retarded child plays a part in the impact on the family. He asserts that "entirely different parental dynamics are operant during the creation of the first child; hopes, expectations, etc. are realized, satisfied, or extinguished with the first born. Later birth of a retardate may be much less traumatic."[215] He cites findings which show that the first born is institutionalized more readily, and suggests that discontent may be highest when the retarded child is the first born.. Wolfensberger also points out that considerable difference in dynamics can be expected in families who have further children.

Family size has been indicated as a factor differentiating the impact of a handicapped child on the family. Mowatt suggests that "families that are large and happy and have a secure place in the community can absorb the difficulties more easily than most."[216] Dow, studying the families of 58 disabled children, with mostly orthepedic difficulties, expected to find a difference in reaction to the disability, by social class. A difference according to social class was not found, but a difference in reaction by family size, with the large family exhibiting a better adjustment, was established. As the author explains it, "a large family, because of involvement in an extensive network of interactions and obligations, was able to avoid an excessive preoccupation with the illness. Because of the necessity of reconciling pre-existing demands with the requirements of the illness, the family is forced to view the disability in its "proper perspective" vis-a-vis those remaining obligations. Thus, the natural tendency toward excessive involvement with the illness is thwarted."[217] In contrast, Dow describes a small family as one in which the family's obligations and interactions are not sufficient to prevent the illness from becoming a major preoccupation and an extreme reaction follows. As he sees it, a small family necessitated an unavoidable concentration of emotional interaction and reward, which is greatly reduced, if not entirely destroyed, by the temporary loss of one member.[218]

Bradshaw and Lawton, investigating stress in families of handicapped children, investigated whether stress varied according to family composition. They felt that the composition of the family might influence the level of stress in a number of ways. Coping with a handicapped child on top of the burdens of other children could lead to greater stress (i.e. larger family - greater stress). Alternatively, they felt that the rewards or supports provided by other children might compensate for the presence of a handicapped child (i.e. larger family - less stress). The researchers found, however, that there was no significant variation in the mothers' level of stress by family size, nor between one- and two-parent families.[219] A significantly lower score was, however, found for mothers whose handicapped child was their only child, which would tend to contradict assertion that adjustment is enhanced by obligations and interactions which distract from the problems of the handicapped child.

B. Positive Adjustment to a Child with a Handicap

A number of researchers, studying families with handicapped children, appear to be intrigued by those families who have made a good adjustment to their situation. They point out that such families do exist, and attempt to determine those qualities that contribute to their positive outlook. Often the qualities described, rather than referring to demographic characteristics, are those of a more subtle nature; the parents' personalities, the strength of their relationship, the way in which they customarily deal with stress, the help and support of relatives. As such, the factors instrumental in bringing about a good adjustment, appear to be often those ones that don't easily lend themselves to measurement, or to manipulation. It may be thus suggested that, attempts to affect real change in the quality of the lives of families with handicapped children, may require some previously untried, perhaps unconventional strategies, aimed toward strengthening aspects of the situation that have not been approached in the past.

Dow's study of parents of 58 disabled children with mostly orthepedic disabilities yielded positive results. He found that "Parents overwhelmingly manifested optimism or a positive attitude toward the concept and actuality of disability. The majority of parents optimistically evaluated the implications of the child's disability, and the reaction of others to this, and expressed willingness to 'expose' the child. In contact with neighbors, friends, the public they felt no shame."[220]

Holt, in an article which specified very clearly the wide range of problems found in families with retarded children, concluded by pointing out "that there were families who managed very well and showed emotional and spiritual reserves that suggested outside help would be superfluous."[221] He describes some of the features that appeared to be associated with a positive adjustment, "The families who managed best were not those in the upper social classes. These parents were usually ambitious for their children and never overcame their frustration and disappointment. The ideal parents were those who, while sufficiently intelligent to appreciate the needs of the child and to have some insight into his difficulties did not have great ambitions, and so they did not constantly display their disappointment." He also found that "Those families were better adjusted who had not concentrated all their hopes and desires upon one child and who had other things to think about, often other problems, so that the defective child was not forever in their minds."[222]

Dorner also found that some families with handicapped children made a positive adjustment to the situation, due to particular characteristics of these families. "It cannot be concluded, however, that a poor quality of life is inevitable in such circumstances (having a child with a severe physical handicap) since there were a number of families, who, because of the resilience of some or all of the members, the supportiveness of the marriage, and so on, had made a good adjustment to the problem of the handicap."[223] Because of the nature of the characteristics which appear to facilitate a good adjustment, however, he points out that it is difficult to determine in advance which families these would be.

Fabrega and Haka also describe parental characteristics as determining the reaction to handicap. They found that the amount of disruption experienced depended not on the degree of the child's retardation, but on the parents' emotional resources. "Emotionally well-balanced parents could adapt to and accept their retarded children more easily than emotionally-driven, grieving parents, so preoccupied with the liabilities and stigma that they are not responsible to the needs of the child."[224] Cohen, discussing the impact of the handicapped child on the family, points out that "how a particular family makes its own adjustment is related to its customary pattern of meeting stress."[225]

Bradshaw and Lawton, investigating stress in mothers of a handicapped child also indicate the importance of parental characteristics. They were surprised to find that variables such as degree of child's handicap, mobility of child, etc. did not make for variation in stress score. Having found unexpectedly few external factors that determined level of stress, they proposed an alternative hypothesis; that the level of stress is determined by internal factors - by the physiology and personality of the mother - and that these internal factors are not affected in any specific way by the external social and physical conditions of the family and the child.[226]

Howell indicates his "tremendous respect for those families who are able to cope successfully" with the raising of a handicapped child. He postulates that these families have several factors in common: 1) The relationship of mother and maternal grandparents is especially important to the mental health of the handicapped child's family.[227] 2) A strong marital relationship - if this alliance is strong, the presence of the handicapped child may bind husband and wife closer, if weak, it may be dissolved by stress. 3) The order of the handicapped child in the sibship and the opportunity for successful parenting of normal children. 4) Presence of adequate, competent, and trusted professional care.

5) A listening professional ear as well as understanding friends. 6) Recreation and a change of pace and activity. 7) Ability to plan ahead relative to household management so that an unexpected event doesn't disrupt family living. 8) Helpful to live near services. 9) Deep sense of religious faith. 10) Opportunities to help others and the ability to help other parents usually represents a reasonably comfortable stage of adjustment.[228]

VI. Some Additional Comments

A. Selected Insights into the Literature

1) Interpretation of Research Findings

Implicit in the question, "What are the effects seen in families with handicapped children" is the added proviso, "because they contain a handicapped child". That is, what is really desired is a determination of the effects that are seen because the family includes a handicapped member, that would not exist if it didn't. The difficulty is, in this respect, as Hannan indicates:

> At times, it is difficult to distinguish the problems of 'normal' child-rearing from those specifically related to mentally-handicapped children. All children get on their parents' nerves, they all make messes and they all need and demand more attention than most adults can normally give them.[229]

Families with only normal children have difficulties, are subjected to stresses and strains and are affected in various ways by the presence of their children. Some families with normal children cope better than others; some may exhibit extreme reactions such as the break-up of the marriage, parents depressions, etc. The question then becomes, do these negative aspects occur in families with handicapped children to an extent that is greater than that in families with only normal children? Answering such a question requires studies that are carefully controlled, that can compare the incidence found in families of the handicapped with that of families of normal children, or of that found in the general population. Many of the studies described above, did not have such controls, but rather pointed out that a particular effect, or problem, was found in a certain percentage of the families with handicapped children under study. Interpretation of the results of such studies must, therefore be carried out with the utmost care, keeping in mind the intrinsic limitations of such results. They cannot be used as evidence that the presence of the handicapped child "causes" certain effects.

2) The Difference between Families with a Handicapped Child and Those with Only Normal Children

Although the state of the art, thus, does not permit an authoritative delineation of the effects that are due to the presence of a handicapped child, some insight can be gained from the literature as to differences between the families, that might make for differences in effects seen. That is, in reading a large amount of material on families with handicapped children, the differences between these families, and those with only normal children, began to be formulated. These differences, both quantitative and qualitative, would be presumed to be the factors that would be the basis for differences in family functioning, and in the impact that raising a child is seen to have on the family members. The following suggestions as to these differences are an attempt to share some initial insights gained. As this was not considered to be an original goal of this discussion, it should not be considered a comprehensive, or systemic, presentation.

The differences between these families and those with only normal children appear to be both quantitative and qualitative. In terms of quantitative differences, it sometimes appears, in reading the literature, that should a family with only normal children have their child care responsibilities multiplied a thousandfold, they would have some feeling of what raising a handicapped child may entail. That is, like families with normal children, there are responsibilities that families with handicapped children must undertake; they get up at night to care for their children, prepare special foods when necessary, care for their children when ill, deal with incontinence, supervise children who can't be left on their own, etc. However, these childcare responsibilities of the families of the handicapped appear to be greater in two ways. First, they often go on for many more years, sometimes a great many more years. Parents of the handicapped may have to be carrying out these same responsibilities for years after their counterparts with normal children have been able to stop worrying about getting up at night, incontinence, constant supervision and so on. Second, the responsibilities can be more intense; illnesses may be very frequent and life-threatening, supervision may have to be almost 24 hours a day.

There are also qualitative differences in the care that is entailed; elements that are involved because the child is handicapped, that are not seen in families with only normal children. Especially for the parents of physically handicapped, care may involve a whole sphere beyond that provided by parents of normal children, and require the mastering of equipment that these parents would never see; wheelchairs, braces, shunts, etc.

It also appears that qualitative differences in the emotional underlay of these families lives can be very great. The whole experience of having a child may be stigmatized when that child is handicapped; the way in which he is regarded, by society, and by his parents may be different from that of a normal child, and many aspects of his life be viewed in a different light. Thought of the child's future, may be especially troubling, when a child is handicapped, raising worrisome doubts, rather than hopeful thoughts of possible achievements.

3) Differences Between the Families of the Mentally and the Physically Handicapped

Some impressions were also gained, in reading through the literature, on a number of differences between those families with mentally retarded, and those with physically handicapped, children. There were a number of particular differences in emphasis that stood out when reviewing the literature in regards to specific aspects. Once again, there is no attempt to present a systematic or comprehensive discussion of this issue, but rather to describe a number of points that became clear.

It appears that, with retardation, because of the mental limitations of the child, parents may have more of a sense of the "line of the future" being disturbed, that the child doesn't carry on the family name and tradition. This aspect was not mentioned in regard to parents of the physically handicapped. Also, there may be no speech, and, if brain damage is involved, bizarre behavior, so that communication with the child may be impaired to a greater extent than in those families with a physically handicapped child. An orientation towards the child as a "normal child with a handicap" may be more difficult for parents of retarded.

With physical handicap, the illness may be progressive and the condition of the child a constant cause of concern. Numerous hospitalizations may be involved to a greater extent than when the handicap is mental. Getting around with the child may be difficult, and involve constant lifting and the use of special equipment, For those children with normal intelligence level, the philosophical meaning of being handicapped may have to be dealt with. The self-awareness of oneself as handicapped appears to be more developed in the physically handicapped than in the mentally retarded. The physically handicapped child may share in an understanding of the stigma with which society imbues his position, and be aware of the reaction of strangers to a greater extent. Parents may, accordingly, have to deal with his reality-based depression to a greater degree than would parents of mentally handicapped.

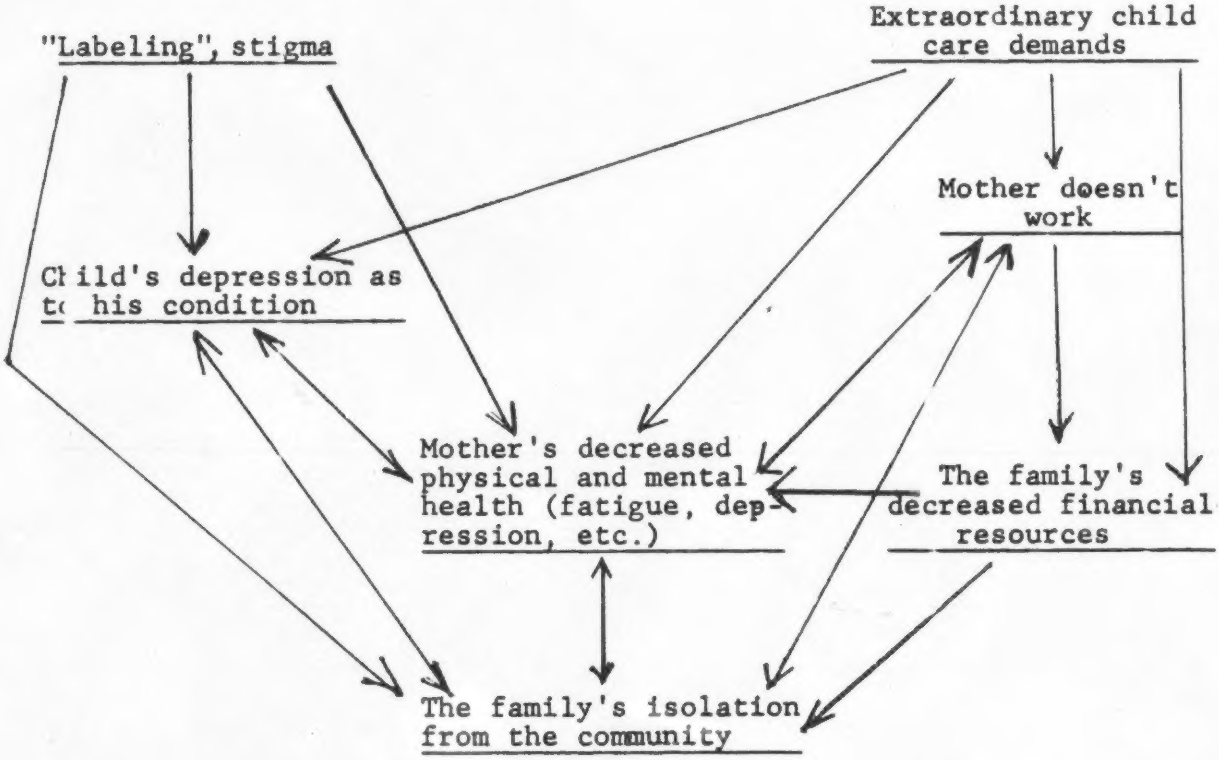
B. The Interrelationship of Effects

1) A Hypothetical Model

In discussing the literature on the effects on the family of having a handicapped child, each effect was discussed individually, as a separate aspect of the impact seen. However, in reality, it appears that the effects described interact with one another. That is, not only, for example, is a mothers' health affected by the presence of a handicapped child, but also, the state of her health contributes to other effects seen, her husband's mental health, the family's relationship to the outside community, etc. In this way, the effects described effect one another in a complicated pattern of interactions.

In attempting to fully understand the impact on the family of living with a handicapped child, it might be useful to attempt to trace this possible interaction of effects so that a feeling for the dynamics involved might be gained. To this end, a diagrammed presentation will be included below, which represents speculation as to how a number of effects described in the literature might interact. As no research as to this is in evidence, this conception is speculative in nature. Each of the effects included in the diagram has been mentioned in the literature; the relationships described between them are hypothetical. The effects don't necessarily interact as is described, but they may do so.

Model of the Interrelationship of Effects


"Labeling", stigma
Extraordinary child care demands
Mother doesn't work
Child's depression as to his condition
Mother's decreased physical and mental health (fatigue, depression, etc.)
The family's decreased financial resources
The family's isolation from the community

2) Explanation of the Relationships Shown in the Model

Two independent variables, the extraordinary child care demands of the handicapped child, and the "labling" and stigma associated with having a handicapped child, are seen as leading to the other effects. The first of these variables is seen as directly contributing to 4 effects: the mother's decreased physical and mental health, the mother's not working, the family's decreased financial resources, and the child's depression as to his condition. These effects, in turn, interact with one another. The mother's not working adversely affects her mental health, and the worse her mental and physical health, the more likely she is not to work. Not working also has a negative effect on the family's financial resources, which is likely to further worsen her mental health. The stigma associated with having a handicapped child contributes to depression in both the child himself, and in the mother, and each of these is likely to affect the other. The stigma involved, the child's depression, the mother's mental and physical state, the fact that the mother doesn't work, and the family's decreased financial resources are all seen as likely contributors to the family's isolation from the community. This, in turn, is seen as a factor further affecting the mother's and the child's, mental health.

It can thus be seen that, even with only a few of the possible effects considered, the picture begins to be very complex; with effects contributing to other effects, in a complicated pattern of interactions. It also becomes clear how a family might become involved in a negative cycle; as a number of aspects begin to go badly, others follow, until the family may find itself in a very bad situation, from which it is difficult to extricate itself.

3) Use of the Model in Program-Planning

In considering interventions aimed at improving the lot of the family with a handicapped child, recourse to such a model may be of use. Understanding the interactions between variables would allow for conceptualization of the projected outcomes of potential programs. The expected, or optimal, effects of a program directed toward a specific goal could be traced. For example, should an information campaign to educate the public about handicap and so, lessen the social stigma, be considered, the influence that this could be expected to have on the families of the handicapped could be formulated (i.e. decreased depression in mother and child, decreased isolation from the community; each of which could be expected to lead to other changes in the configuration of factors).

Also, reference to such a model would permit identification of those factors that play a key role in determining the family's situation; those which, if successfully manipulated, would be expected to effect the greatest change, by influencing the largest number of variables. Programs aimed at such key variables would, thus, have the greatest likelihood of improving the family's condition.

In terms of this hypothetical model, for example, the predominance of the mother's physical and mental health status is clear. Should this status be improved, and the mother not be depressed, the whole outlook changes as the influence on other variables is felt. She might then work, which would help the family finances and further improve her mental health, the family would tend to be less isolated from the community, and the child himself would feel better about his situation. A systematic consideration of the interaction of factors, as set forth in this hypothetical model, is thus suggested as a potential aid to rational program-planning.

VII. Notes

1. The lack of material on handicapped offsprings as adults within the family may reflect a number of factors. The number of adult handicapped living with their families may be small, due to death or institutionalization. This may also reflect the choice of subject by the researchers, who may find families with handicapped children a more accessible, dramatic or fundable focus of investigation.

2. See model in final section, for a suggestion as to an alternate way to establish the importance of a various effect; the degree to which it effects other aspects of family functioning.

3. It is considered fruitless to enter into a discussion as to whether, a mother's depression, for example, is more likely attributable to her dismay at having produced an imperfect child, or to the considerable work his care involves. The goal therefore would be to indicate the existence of both these elements, and to cite them as factors likely playing a part in her low spirits.

4. Holt, K.S., 1958a, "The Home Care of Severely Retarded Children", Pediatrics 22, 4, 1, 744-55, p. 750.

5. Kew, Stephen, 1975, Handicap and Family Crisis, London: Pitman, p. 159.

6. Ibid.

7. McMichael, Joan K., 1971, Handicap: A Study of Physically Handicapped Children and their Families, London: Staples Press, p. 76.

8. Birenbaum, Arnold, 1971, "On Managing a Courtesy Stigma", J. of Health and Social Beh., 11:3, pp. 196-206, p. 196.

9. Wolfensberger, Wolf, and Menolascino, Frank J., 1970, "A Theoretical Framework for the Management of Parents of the Mentally Retarded", in Menolascino, Frank J., ed. Psychiatric Approaches to Mental Retardation, New York: Basic Books, p. 475.

10. Ibid.

11. Ibid., p. 477.

12. This section is based on Ryckman, David B., and Henderson, Robert A., 1965, "The Meaning of a Retarded Child for his Parents: A Focus for Counselors", Mental Retardation (August) pp. 4-7.

13. Wolfensberger, Wolf, 1968, "Counseling the Parents of the Retarded", in Baumeister, Alfred A., ed., Mental Retardation: Appraisal, Education and Rehabilitation, Chicago: Aldine Publishing Company, pp. 329-300, p. 332.

14. It may be noted that the literature upon which this section is based, refers only to the mentally retarded. It might be that, for example, physically handicapped children of normal intelligence do not involve the same reappraisal of parental feelings and aspirations. In the absence of research findings, it might be interesting to speculate upon factors that might influence this; degree of handicap, presence or absence of bizarre symptology, level of intelligence, parental attitudes towards the dysfunction involved. It appears possible that a wide range may exist in regards to the meaning to parents of having a handicapped child, from only a slight reappraisal of expectations and goals, to feelings that no normal expectations can be made in regards to the child.

15. McMichael, op. cit., p. 78.

16. Ibid., p. 77.

17. It is clear that this is a relationship that goes both ways; the family's emotional reaction will help to determine the child's. See final section for a discussion of the interaction of factors.

18. McMichael, op. cit., p. 78.

19. Ibid., p. 56.

20. Kolin, I.S., et al, 1971, "Studies of the school-age child with meningomyelocele: Social and emotional adaptation", *J. of Pediatrics*, 78:6 (June), pp. 1013-9, p. 1018.

21. Minde, Klaus, et al., 1972, "How They Grow Up: 41 Physically Handicapped Children and Their Families", *Amer. J. Psychiat.*, 128:12 (June), pp. 104-109, p. 107.

22. Ibid., p. 108.

23. Dorner, S., 1975, "The Relationship of Physical Handicap to Stress in Families with an Adolescent with Spina Bifida", *Develop. Med. Child. Neur.*, 17, pp. 765-776, p. 769.

24. Ibid., p. 769.

25. Wolfensberger and Menolascino, op. cit., p. 476.

26. Anderson, Elizabeth and Spain, Bernie, 1977, *The Child with Spina Bifida*, London: Methuen, p. 72.

27. Kew, op. cit., p. 158.

28. Ibid.

29. Hannam, Charles, 1975, *Parents and Mentally Handicapped Children*, Harmondsworth: Penguin Books, p. 73.

30. Howell, S.E., 1973, "Psychiatric Aspects of Rehabilitation", *Pediatric Clinics of North America*, 20, 203, p. 205.

31. Holt, op. cit., p. 746.

32. Ibid.

33. Ibid.

34. Mercer, Jane R., 1966, "Patterns of Family Crisis Related to Reacceptance of the Retardate", Amer. J. Men. Def., 71, pp. 19-32, p. 26.

35. Ibid., p. 27.

36. Ibid., p. 29.

37. Hannam, op. cit., p. 73.

38. Ibid.

39. Ehlers, W.H., 1966, Mothers of Retarded Children: How They Feel, Springfield: Charles C. Thomas, p. 23.

40. Barsch, Ray H., 1968, The Parent of the Handicapped Child, Springfield: Charles C. Thomas, p. 355.

41. Begab, Michael J., 1966, "The Mentally Retarded and the Family", in Philips, Irving, ed. Prevention and Treatment of Mental Retardation, New York: Basic Books, pp. 71-84, p. 76.

42. Ibid., p. 77.

43. Ibid., p. 78.

44. Holt, op. cit., p. 746.

45. Richards, I.D. and McIntosh, H.T., 1973, "Spina Bifida Survivors and Their Parents: A Study of Problems and Services" Devel. Med. Child Neur., 15, 292-304, p. 297.

46. Bradshaw, J. and Lawton, D., 1978, "Tracing the Causes of Stress in Families with Handicapped Children", Br. J. Soc. Wk., 8:2, pp. 181-191, p. 187.

47. Begab, op. cit., p. 78.

48. Ibid., p. 80.

49. Freeston, B.M., 1971, "An Enquiry into the Effect of a Spina Bifida Child Upon Family Life", Devel. Med. Child Neur., 13, pp. 456-61.

50. Drotar, D. et al, 1975, "The adaptation of parents to the birth of an infant with a congenital malformation", Pediatrics, 56, pp. 710-717, p. 715.

51. MacKeith, Ronald, 1973, "The Feelings and Behaviour of Parents of Handicapped Children", Devel. Med. Child Neur., 15, pp. 524-527, p. 526.

52. McMichael, op. cit., p. 87.

53. Ibid., p. 89.

54. Ibid., p. 113.

55. Anderson and Spain, op. cit., p. 69.

56. Ibid.

57. Wolfensberger and Menolascino, op. cit., p. 476.

58. Wolfensberger, op. cit., p. 330-335.

59. Wolfensberger, op. cit., p. 331.

60. Cohen, Pauline C., 1962, "The Impact of the Handicapped Child on the Family", Soc. Casework, XLIII: 3 (Mar.), pp. 137-142, p. 138-9.

61. Drotar et al, op. cit., 711-2.

62. Wolfensberger, op. cit., p. 347.

63. Ibid., p. 334.

64. Willner, S.K., and Crane, R., 1979, "A Parental Dilemma: The Child with a Marginal Handicap", Soc. Casework 60:1 (Jan.), pp. 30-35, p. 32.

65. Wolfensberger, op. cit., p. 334.

66. Ibid.

67. Ibid.

68. Ibid., p. 335.

69. Holt, op. cit., p. 747.

70. Ibid.

71 Ibid., p. 748.

72. The Carnegie United Kingdom Trust, 1964, Handicapped Children and Their Families, Edinburgh: T & A Constable Ltd., p. 73.

73 Ibid., p. 78.

74 Ibid., p. 260.

75. Howell, op. cit., p. 205.

76. Ibid.

77. Ibid.

78. Walker, J.H. et al, 1971, "Spina Bifida and the Parents", Dev. Med. Child Neur., 13, p. 462-75., p. 470.

79. McMichael, op. cit., p. 90.

80. Ibid., p. 122.

81. Ibid., p. 123.

82. Ibid., p. 124.

83. Dorner, op. cit., p. 772.

84. Ibid.

85. Erickson, Marilyn, 1969, "MMPI Profiles of Parents of Young Retarded Children", *Amer. J. Men. Def.*, 73: 5 (Mar.), p. 728 ff, p. 730.

86. Tew, Brian, and Laurence,K.M., 1973, "Mothers, Brothers and Sisters of Patients with Spina Bifida", *Dev. Med. Child Neur.*, Supplement 29, 15: 6, p. 69-75, p. 74.

87. Ibid.

88. Bradshaw and Lawton, op. cit., p. 183.

89. Ibid.

90. Ibid., p. 189.

91. Cummings, S.T. et al, 1966, "Effects of the Child's Deficiency on the Mother: A Study of Mothers of Mentally Retarded, Chronically Ill and Neurotic Children", *Amer. J. Orthopsy.*, 36, p. 595-605, p. 595.

92. Ibid., p. 605.

93. Ibid.

94. Love, H.D., 1970, *Parental Attitudes Toward Exceptional Children*, Springfield: Charles C. Thomas, p. 29.

95. Cummings, S.T. et al, 1976, "The Impact of the Child's Deficiency on the Father: A Study of Mentally Retarded and Chronically Ill Children", *Am. J. Orthopsy.*, 46: (April), pp. 245-255, p. 251.

96. Ibid., p. 252.

97. Ibid., p. 253.

98. Ibid., p. 253.

99. Waisbren, S.E., 1980, "Parents' Reactions after the Birth of a Developmentally Disabled Child, Amer. J. Men. Def., 84: 4, pp. 345-351, p. 348.

100. Ibid.

101. Ibid.

102. Gath, Ann, 1977, "The Impact of an Abnormal Child Upon the Parents", Brit. J. Psychiat., 130, pp. 405-10, p. 408.

103. It is of interest that these two studies, which did make provisions for comparison with mothers of normal children, both led the researchers to conclude that differences were not significant. However, a number of points should be considered. The samples are relatively small, especially in the Waisbren study where couples differed not only on the mental status of their children but also on country of residence. Also, both studies focused on very young children, with a maximum age of two years. It is possible that mental strain of parents with retarded child is more noticeably different from that of parents with normal children at older ages for a number of reasons; behavior differences between

retarded and normal may be more striking in older children and the demands of child rearing of normal children in early ages may be so great that mental health of parents tends to be at a low point. Also, as neither study indicated the intelligence level of the retarded children, the severity of the retardation may have been less than in other studies described.

104. Mandelbaum, A. and Wheeler, M.M., 1960, "The Meaning of a Defective Child to Parents", Soc. Casework, XLI: 7 (July), pp. 360-367, p. 362.

105. Barsch, op. cit., p. 349.

106. Ibid.

107. Drotar et al, op. cit., p. 716.

108. Holt, op. cit., p. 749.

109. Ibid., p. 750.

110. Gath, op. cit., p. 408-9.

111. Ibid., p. 409.

112. Ibid.

113. As it was not possible to gain access to this book, the comments of two reviewers, quoted below, were used.

114. Sinson, Janice, 1979, "Review of Gath, Ann, Down's Syndrome and the Family: The Early Years, London: Academic Press, 1978", Brit. J. Men. Subnor., No. 48, (June), p. 50.

115. Oswin, Maureen, 1979, title as above, Devel. Med. Child Neur., 21: 3 (June), pp. 406-7.

116. Pillig, Doria, 1973, The Handicapped Child: Research Review, Vol. III, London: Longman Group Ltd., p. 41.

117. Ibid.

118. Ibid.

119. Farber, B., 1968, Mental Retardation: Its Social Context and Social Consequences, Boston: Houghton Mifflin, p. 162.

120. Pillig, op. cit., p. 41.

121. Ibid., p. 42.

122. McMichael, op. cit., p. 89.

123. Ibid., p. 122.

124. Ibid., p. 113.

125. Walker, op. cit., p. 470.

126. Freeston, op. cit., p. 458.

127. Dorner, op. cit, p. 772.

128. Tew et al, 1974, "Must a Family with a Handicapped Child be a Handicapped Family?" Devel. Med. Child Neur., 16: 6, Supple. No. 32, pp. 95-98, p. 95.

129. Ibid., p. 96.

130. Ibid., p. 97.

131. Ibid., p. 97.

132. Kolin et al., op. cit., p. 1017.

133. Ibid.

134. Martin, Patricia, 1975, "Marital Breakdown in Families of Patients with Spina Bifida Cystica", Devel. Med. Child Neur., 17, pp. 757-764, p. 761.

135. Ibid.

136. Kew, op. cit., p. 51.

137. The Carnegie United Kingdom Trust, op. cit., p. 79.

138. Tizard and Grad, cited by Farber, op. cit., p. 160.

139. Mandelbaum and Wheeler, op. cit., p. 363.

140. Barsch, op. cit., p. 200.

141. Kolin et al, op. cit., p. 1017.

142. McMichael, op. cit., p. 116.

143. Holt, K.S., 1958b, "The Influence of a retarded child upon family limitation", J. Men. Def. Res., 2, 28-34.

144. Holt, 1958a, op. cit., p. 748.

145. Tizard, and Grad, cited by Pillig, op. cit., p. 37.

146. The Carnegie United Kingdom Trust, op. cit., p. 79.

147. Begab, op. cit., p. 76.

148 Kew, op. cit., p. 52.

149. Richards and McIntosh, op. cit., p. 297.

150 McMichael, op. cit., p. 64.

151. Farber, op. cit., p. 163.

152. Farber, op. cit., p. 165.

153. Richards and McIntosh, op. cit., p. 297.

154. Tizard and Grad, cited in Pillig, op. cit., p. 37.

155. The Carnegie United Kingdom Trust, op. cit., p. 79.

156. Farber, op. cit., p. 160.

157. Wolfensberger, op. cit., p. 346.

158. Kew, op. cit., p. 58.

159. Bradshaw and Lawton, p. 185.

160. Holt, 1958a, op. cit., p. 747.

161. Kew, op. cit., p. 52.

162. Barsch, op. cit., p. 350.

163. Meyerowitz and Kaplan, cited by Farber, op. cit., p. 161.

164. Howell, op. cit., p. 205.

165. Farber, op. cit., p. 160.

166. Ibid.

167. Ibid., p. 161.

168. Kew, op. cit., p. 61.

169. Ibid., p. 62.

170. Ibid.

171. Ibid., p. 63.

172. Walker, op. cit., p. 470.

173. McMichael, op. cit., p. 69.

174. Ibid., p. 70.

175. Holt, 1958a, op. cit., p. 748.

176. Ibid., p. 750.

177. Dorner, op. cit., p. 772.

178. Barsch, op. cit., p. 343.

179. The importance of control groups, of parents of normal children, becomes clear in considering an issue such as this one. That is, even if it is asserted that it is not the presence of the handicapped child that leads to isolation of the family, but rather their attitude towards joining in community activities, it has yet to be shown that isolationist attitudes are not more common among families with a handicapped child. i.e. Is the percent of "joiners", and that of "loners" the same for families with handicapped and normal children?

180. Bradshaw and Lawton, op. cit., p. 186.

181. This concept can be compared to Farber's postulation of "home oriented" families as one of three theoretical types of family organization developed by parents of a retarded child. In such families "parents are seen as completely sacrificing their life chances for family cohesion" (Farber, op. cit., p. 165).

182. Schaffer, H.R., 1964, "The 'Too-cohesive' family: A form of group pathology", Inter. J. Soc. Psych., 10, p. 266.

183. Tew et al, op. cit., p. 96.

184. McMichael, op. cit., p. 62.

185. Ibid., p. 70.

186. Ibid., p. 71.

187. Holt, 1958a, op. cit., p. 748.

188. Plaza Hotel, 12/6/80.

189. Bradshaw and Lawton, op. cit., p. 186.

190. McMichael, op. cit., p. 102.

191. Ibid., p. 127.

192. Richards, op. cit., p. 297.

193. Tew and Laurence, op. cit., p. 74.

194. Pillig, op. cit., p. 46.

195. Ibid.

196. Holt, 1958a, op. cit., p. 747.

197. Ibid., p. 750.

198. Ibid., p. 747.

199. Barsch, op. cit., p. 348.

200. Wolfensberger, op. cit., p. 341.

201. Pillig, op. cit., p. 46.

202. Farber, op. cit., p. 164.

203. Pillig, op. cit., p. 47.

204. Farber, op. cit., p. 154.

205. Ibid.

206. Ibid.

207. Ibid., p. 155.

208. Farber's theory that SES determines the crisis that the family experiences, does not appear to have been tested empirically. It is perhaps, a somewhat extreme view of the situation. It may be more likely that both types of considerations play a part in the crisis for all families. That is, all families with a handicapped child would be expected to have to deal with both the philosophical meaning of having a handicapped child, and the practical problems of care child and re-organization of daily life that are entailed. It may be true that families in different SES groups focus more on one aspect

of the crisis than the other, but it is difficult to believe that both aspects don't have to be considered. Also, empirical testing of such a hypothesis may be difficult. Should it be found that families in the lower SES groups do seem to focus more on the practical problems of organizing daily life to accomodate a retarded child, than those in the higher SES group, this might be as well explained by the fact that their limited resources make the practical problems more difficult to solve, as by an assertion that it is due to their investing the label of retardation with a different meaning.

209. Ehlers, op. cit., p. 41.

210. Ibid., p. 43.

211. Farber, op. cit., p. 156.

212. Cummings et al, 1969, op. cit., p. 603.

213. Zuk, cited by Wolfensberger, op. cit., p. 344.

214. Kolin, op. cit., p. 1017.

215. Wolfensberger, op. cit., p. 346.

216. Mowatt, Marian, 1970, "Group Therapy Approach to Emotional conflicts of the Mentally Retarded and their Parents", in Menolascino, Frank J. ed., Psychiatric Approaches to Mental Retardation, New York: Basic Books, p. 422.

217. Dow, T.E. 1966, "Optimism, Physique and Social Class in Reaction to Disability", J. Health Hum. Beh., 7: 1, pp. 14-19, p. 16.

218. Ibid.

219. Bradshaw and Lawton, op. cit., p. 185.

220. Dow, op. cit., p. 15.

221. Holt, 1958a, op. cit., p. 753.

222. Ibid., p. 754.

223. Dorner, op. cit., p. 773.

224. Fabrega, H. and Haka, K.H., 1967, "Parents of mentally handicapped children", Arch. Gen. Psych., 16, pp. 202-9, p. 207.

225. Cohen, op. cit., p. 138.

226. Bradshaw and Lawton, op. cit., p. 189.

227. This tends to support Farber's assertion that"when the parents of a retarded child are in frequent contact with the wife's mother, marital integration tended to be high...Ordinarily the wife's mother showed much sympathy and understanding for her daughter's situation." (op. cit., p. 162).

228. Howell, op. cit., p. 205.

229. Hannam, op. cit., p. 73.